

EFFECTS OF PLACEMENT IN AN INTERMEDIATE CARE
FACILITY FOR THE MENTALLY RETARDED

By

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by

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The purpose of this study was to examine the effects of placement in a federally funded Intermediate Care Facility for the Mentally Retarded (ICF/MR) training program as opposed to placement in a more traditional care unit at the same institution. Conflicting results in the literature indicated a need for research on the effects of the program.

The progress of 158 moderately, severely, and profoundly retarded subjects living in a state institution was compared with that of 279 control subjects. Profoundly retarded ICF/MR subjects were further divided by number of major physical handicaps.

Social Age, as measured by the Vineland Social Maturity Scale, was found to increase significantly for all ICF/MR subjects but for none of the non-ICF/MR conditions. Progress for moderately and severely retarded non-ICF/MR subjects was not significant during the year following an institutional reorganization which attempted to provide equal services to both ICF/MR and non-ICF/MR units. Implications of the significant progress made by profoundly retarded control

subjects during this year were questionable. Age at institutionalization, number of years lived in the institution before placement into an ICF/MR unit, and length of time spent in ICF/MR were all found to have no relation to progress.

Twelve case studies examined individual response to placement in ICF/MR and some possible reasons for progress or lack thereof.

Subjects in the ICF/MR program made significant gains in Social Age as opposed to those living in more traditional care units at the same institution even after improvement of services in the traditional units. No demographic or diagnostic characteristics were found to be predictive of success in the ICF/MR program with the possible exception of the presence of psychosis in addition to a diagnosis of mental retardation.

CHAPTER I INTRODUCTION

Mental retardation is an age-old tragedy and our reactions to it and treatment (or lack thereof) have varied greatly throughout the years. The birth of a retarded child has been viewed alternately as a punishment from God and as a blessing, and response to the child has ranged from total neglect and abuse to total acceptance and lack of any demands or expectations. Current work has established the ability of retarded persons to learn and develop and now concentrates on finding the best methods for promoting developmental growth.

Background of the Study

More than six million people in the United States have some degree of mental retardation. This population ranges from those known as "six-hour retardates," mildly retarded persons who do poorly in school but have adequate adaptive and social skills for daily functioning (Anderson, 1981), to the most profoundly retarded and handicapped individuals who are passive captives of their environment. The more severely retarded persons are found mainly in institutional settings (Eyman & Borthwick, 1980).

For many years, the profoundly retarded were thought to be untrainable and so received only minimal custodial attention (Stainback

& Stainback, 1983). Recent interest and legislation have focused on the adaptive needs and potential of developmentally delayed persons (Turnbull & Turnbull, 1978). Enacting legislation and guaranteeing the rights of the mentally retarded are only beginning steps, however, and effective implementation strategies have yet to be definitively outlined. Several directions are now being explored including intensive training, improvement of living conditions, and deinstitutionalization of residents into the community (Gibson & Fields, 1983; Landesman-Dwyer, 1981). These issues will be discussed in greater detail in Chapter II but the point for now is that awareness of the historical dehumanization of the mentally retarded has reached the public forum and options for correcting past injustices are being explored.

Sunland Center in Gainesville, Florida,¹ is a state institution for the mentally retarded. Originally established in 1922 as the "Florida Farm Colony for Epileptic and Feeble-Minded," it is today an attractive collection of brick cottages, support departments, and hospital. The majority of cottages are unlocked so that residents can go inside and out at will and those who are capable travel around the campus by themselves when going to school, work, bank, or canteen. Prevocational training departments in each unit prepare residents for paid work positions in the institution's sheltered work shops.

¹There were initially six widely dispersed Sunland Centers located throughout Florida. Two changed their names and two closed due to physical plant inadequacies so that there are now only two "Sunland Centers" in Florida. All references to Sunland in this study refer to the institution located in Gainesville.

The majority of clients presently residing at Sunland fall into the severe and profound levels of retardation since most moderately and mildly retarded residents have been moved to community placements. A significant number of the residents remaining in the institution have some degree of visual, auditory, and/or motor deficit.

Statement of the Problem

Despite substantial individual differences within the mentally retarded population, there has been a marked tendency in the literature to consider limited numbers of variables when studying or devising treatment plans. Frequently, the only designated independent variable has been the subject's IQ level (Finn, 1983; Sandler & Thurman, 1981). Response to training and environment has, however, been shown to be dependent on other factors such as functioning level prior to treatment (Kleinberg & Galligan, 1983; Landesman-Dwyer, 1981) and size of institution (Baroff, 1980). Further, the quality of attention given to residents is influenced by staff perception of the resident's attractiveness and likability in addition to mental level (Dailey et al., 1974). Few studies have measured intervention effects using an objective scale of adaptive development (Lemanowicz et al., 1980). Measures such as decreased verbal dependency and imitativeness, and increased behavioral variability as defined by motivation on a circular maze test (Balla, Butterfield, & Zigler, 1974), are interesting but not readily generalizable to treatment. Additionally, most studies have used a cross-sectional rather than longitudinal design so that effects have not been examined over time (Lemanowicz et al., 1980).

The present study examined six years of longitudinal data, looked at several variables such as number of physical handicaps, age at institutionalization, and time spent in traditional custodial care before placement in an intensive training program, and made specific treatment recommendations.

Intermediate Care Facility for the Mentally Retarded

A federally funded program, Intermediate Care Facility for the Mentally Retarded (ICF/MR), has been implemented nationwide in order to provide optimum living and training conditions for mentally retarded persons. Funded under Title XIX of the Social Security Act (Medicaid), ICF/MR units function under strict guidelines and accountability standards. The program is designed to provide a stimulating training environment for large numbers of institutionalized residents and to prepare them for placement in the community. The ICF/MR program units provide intensive and individualized training to residents in all areas of need including self-care and daily living, academic, social, motor, speech, and job-related skills, as well as any medical, occupational, or physical therapy services. The following conditions are necessary to qualify for ICF/MR placement:

any person who has reached his 18th birthday and has an IQ of 49 or less or who has an IQ of 50-69 with an additional disability such as blindness, deafness, etc. Any person under 18 years of age with an IQ of 59 or less or who has an IQ of 60-69 with an additional disability. These persons must have an income no greater than \$505.00 per month and total assets no greater than \$1,500. (State of Florida pamphlet ICF/MR? Department of Dealth and Rehabilitative Services [no date or publication number given])

Sunland ICF/MR

Twenty-eight of the fifty cottages at Sunland Center are licensed ICF/MR residences. The first unit (Facility I) of 120 residents received its ICF/MR license in 1977 and new units were added as funds became available to meet physical plant renovation requirements. Facility II came on line in 1979; Facility III in 1980; Facility IV in 1981; and one-half of Facility V in 1982. There are no plans at present for further expansion of the program at Sunland.

The ICF/MR program is supported by federal (56%) and state (44%) funds. The maximum payment per client per month is \$1,064.00, depending on the particular needs of the client. Guidelines and accountability are strict. For example, each client must have a minimum of eighty square feet of living area if in a private room, or sixty square feet if living in a room of two to four persons. Families are encouraged to visit at any time and a resident is permitted to spend up to thirty nights at home per year. Medical care is provided, and each client must have a medical, pharmaceutical, and dietary review every sixty days. A direct care staff to client ratio of one to two is required for ambulatory and one to one for non-ambulatory residents. Additionally, a cottage manager and training staff are assigned to each cottage. Clients may not have more than three consecutive hours of unstructured time any time of the day, any day of the week. Standards are monitored through biannual surveys conducted by the Office of Licensure and Certification (OLC) and Medicaid, as well as by an in-house Quality Assurance Team in addition to monthly facility self-monitoring.

Each Sunland unit of 120 clients is supported by a professional staff of two psychologists, social workers, speech therapists, occupational therapists, vocational trainers, and one dietician. All clients are evaluated yearly and their progress over the past year assessed. Training goals for each client's coming year are developed at his or her annual habilitation plan meeting. Progress in all training programs is reviewed at least quarterly and often monthly by an Interdisciplinary Team (IDT) which consists of cottage staff, all therapists who provide services to each client, and the social worker, nurse, and program coordinator (Qualified Mental Retardation Professional--QMRP).

Prior to November 1982 Sunland non-ICF/MR cottages had a high staff-client ratio and provided traditional custodial care. Two or three direct care staff each shift performed all housekeeping and caretaking activities for one cottage of twenty to thirty residents, and one or two training aides were supervised by a behavioral program specialist working out of a central programming department. In November of 1982 the Center underwent a unitization process during which all therapy departments were dissolved and placed under the authority of the head administrator in each unit. All facilities were assigned the same number of direct care, training, and therapy staff except that non-ICF/MR cottages received no housekeepers. All facilities were then charged with meeting ICF/MR standards so that all clients at Sunland would receive identical training and care whether they lived in ICF/MR or in non-ICF/MR units.

In practice, however, this attractive goal has not been met and there remains a training/care differential between the two kinds of living units. Non-ICF/MR cottages remain more crowded than their ICF/MR counterparts and ICF/MR staff vacancies at times take priority because licensing and federal funding are jeopardized if full services are not consistently provided to ICF/MR residents. The absence of housekeeping staff in non-ICF/MR requires that custodial (direct care) staff perform housekeeping chores and considerably lessens the amount of time they can devote to training clients, work routinely performed by the direct care staff in ICF/MR. The assignment of permanent nursing staff to ICF/MR cottages enables clients to receive training in health-care needs such as proper handwashing and water fountain skills for hepatitis carriers, disinfection of bathing mats for those with foot fungus difficulties, adequate hydration for those taking medications, and first aid programs. Unitization narrowed the services gap between the two halves of Sunland but has not negated it despite vigorous efforts to standardize the entire Center.

Maladaptive Behaviors

Many clients at Sunland exhibit a wide range of inappropriate behaviors ranging from mild, annoying behaviors to life-threatening self-abuse and aggression. Control of client behaviors is accomplished through a combination of behavioral intervention and administration of psychotropic (mind-affecting) medications.

Behavioral intervention

Behavioral intervention is the primary approach at Sunland when attempting to bring problematic behaviors under control. Procedures must adhere to strict guidelines developed by the Florida Department of Health and Rehabilitative Services (HRS). Any procedure which intrudes into client rights must be approved and monitored by a state-certified (Level III) committee. Any approved aversive (unpleasant) procedure must be paired with a heavy reinforcement schedule (pleasant consequences for appropriate behavior). Unpleasant physical interventions such as spanking or electric shock are never permitted.

Behavioral techniques commonly employed at Sunland include

1. Positive Reinforcement: Response-contingent presentation of a stimulus which maintains or increases the frequency of the response;
2. Differential Reinforcement: Reinforcement for a response under one stimulus condition but not under other stimulus conditions, e.g., a specific behavior is encouraged in one situation but the same behavior emitted in an inappropriate situation is not reinforced;
3. Social Disapproval: Response-contingent use of certain statements and facial expressions which results in a decrease in the inappropriate behavior (verbal abuse and humiliation are not permitted);
4. Time-Out:
 - a. Exclusion Time-Out I: The prompt and temporary removal of a client from an activity contingent upon the occurrence of specified inappropriate behaviors;
 - b. Exclusion Time-Out II: The prompt and temporary removal of a client from an activity and placement behind a screen or other

visual obstruction after exhibition of specified inappropriate behaviors;

c. Seclusion Time-Out: Temporary confinement in a room contingent upon the occurrence of a specified maladaptive behavior; the opportunity to acquire or contact reinforcing stimuli is suspended.

5. Response Cost: Removal, postponement, or omission of the presentation of a reinforcer after a targeted maladaptive behavior has occurred;

6. Extinction: The discontinuation of identified reinforcing consequences results in a decrease in the rate, force, duration, or other characteristics of the targeted maladaptive behavior.

Once an intervention strategy is developed and approval obtained from the Level III committee, all staff involved in its implementation are trained and appropriate documentation set up. Results are regularly monitored and changes in the program made as the targeted behavior either responds to the intervention or fails to show improvement.

Medical intervention

As stated earlier, behavioral intervention is the treatment of choice when dealing with clients who exhibit problematic behaviors. At times, though, inadequate response to consequences or the severity of a target behavior warrants prescription of psychotropic (mind-affecting) medications in addition to programming. Medications commonly prescribed at Sunland include antipsychotics (also called neuroleptics and major tranquilizers) such as Thorazine, Mellaril,

Prolixin, Stelazine, Navane, Haldol; minor tranquilizers such as Librium; the anti-manic medication Lithium Carbonate; and anti-depressants such as Elavil, Sinequan, Xanax, and Tofranil (DeGennaro et al., 1981; Harris, 1981a,b,c,d).

Major tranquilizers are used to treat serious symptoms such as agitation and rage, overreaction to sensory stimuli, combativeness and hostility, hallucinations, delusions, and paranoia. They are administered orally at Sunland, and residues remain in the fatty tissues for two to three months after discontinuation.

Possible side effects of the major tranquilizers include sedation, dizziness, diminished sex drive, difficulty ejaculating, weight gain, a lowered seizure threshold with concurrent increased risk of seizure activity, and anticholinergic effects such as nasal congestion, dry mouth, blurred near vision, constipation, and urinary retention. These side effects often dissipate within days or weeks of starting the medication. Of more concern is tardive dyskinesia, a neurological condition which may occur after long-term use of antipsychotic medications. This often irreversible condition is manifested by tremors and tongue thrusting. The disorder is usually masked by the drug and is therefore often not discovered until the medication has been discontinued.

Minor tranquilizers such as Librium are typically used to help a client adjust to a particularly stressful situation and are prescribed on a short-term basis. Lithium Carbonate has a calming effect on some agitated or hyperactive clients. Antidepressants are used to treat long-term symptoms of depression.

Clients receiving antipsychotic medications are reviewed regularly by the physician, psychiatrist, and psychologist, and attempts are constantly made to reduce or discontinue dosages. As of May 1984, 29% of the client population at Sunland (257 of 886 residents) received psychotropic medications: 187 were prescribed one drug; sixty-seven received two kinds of drugs; and three clients received three separate medications (Bates, 1984). Less than one year later (Bates, 1985), the usage of major psychotropic medications had decreased to 21.4% of the total population of 860 clients and the use of minor agents, especially Xanax, had increased. Interestingly, fewer ICF/MR clients required psychotropics in 1985 than did residents of non-ICF/MR cottages. This finding agrees with the results of a nursing study conducted at Sunland (Steadham, 1983) which found that minor psychotropic agents are more often prescribed for ICF/MR clients and that the major psychotropics are more often prescribed for non-ICF/MR residents. Steadham also found that injuries sustained by clients in ICF/MR require significantly less medical intervention (are less serious) than those which occur in non-ICF/MR units. She suggests that differences may be due to the greater amount of programming and living space provided by ICF/MR.

Interdisciplinary Team

Decisions about client treatment are made by unit Interdisciplinary Teams (IDT) composed of a chairperson (QMRP), psychologist, social worker, nurse, cottage manager and staff, and therapists. These teams meet yearly to formulate each client's Habilitation Plan (Hab Plan),

which is an evaluation of the client's progress during the preceding year and establishment of formal training goals for the coming year. This same team then meets monthly to discuss each client's progress toward all of the goals established in the Hab Plan. At these meetings the different therapists and trainers are able to share any concerns they may have about the client's performance and health, and suggest changes in programming so that ICF/MR guidelines requiring client progress are met.

Community Placement

At the time of each client's Hab Plan the IDT must justify continued placement of that client in ICF/MR and must also project his or her best probable placement in three to five years. Many of the clients in the ICF/MR program are felt to benefit from their current living arrangement and so their recommended placement remains ICF/MR. Some clients progress to the point where community living is indicated and so Sunland ICF/MR placement is recommended for them only until an appropriate community setting becomes available. In reality, however, clients frequently remain at Sunland for several years after being recommended for community placement because of the shortage of outside living arrangements.

Several placement options are available in Florida for mentally retarded persons:

1. Community ICF/MR: Operates under the same training guidelines and accountability standards as Sunland ICF/MR but is restricted to sixty clients and provides a noninstitutional atmosphere;

2. Group Home: Serves four to sixteen clients in a family type situation and allows maximum integration into normal neighborhood activities. Provides some specialized care and/or training based on needs of residents and classification of the home;
3. Foster Home: Serves one to three clients and provides supportive family atmosphere and specialized care and/or training based on needs of residents and classification of the home.

The above types of placement are alternatives to the traditional institutional placement for the mentally retarded and ideally provide a less restrictive environment. Their strengths and weaknesses will be discussed in the next chapter. Community ICF/MR facilities operate under the same standards as Sunland ICF/MR but often provide contracted therapy services rather than maintaining full-time professional staff. Group and foster homes do not fall under ICF/MR guidelines and offer more traditional custodial services. Residents of these homes often spend much of their day at a sheltered work shop.

The ICF/MR program imposes firm structure and expectations on its residents. Individualized treatment plans developed for all clients help them achieve the highest level of adaptive and intellectual functioning of which they are capable. The ICF/MR program has upgraded the traditional institutional model which has focused only on residents' basic health and care. Current practice at Sunland attempts to provide care commensurate with ICF/MR standards in both its licensed and unlicensed units. Emphasis is placed on training and eventual movement of residents into less restrictive community placements.

Purpose of the Study

The purpose of this study was to investigate whether persons living in a state institution for the mentally retarded show greater adaptive development when living in a federally funded ICF/MR training program than in traditional care units at the same center.

A great deal of effort and expense are required to run an ICF/MR facility and maintain accountability, and the little research that has been done on the effectiveness of the ICF/MR program has shown conflicting results. Both positive (Bedinger & Miles, 1982; Ellison, 1983; Witt, 1981) and negative findings (Bible & Sneed, 1976; Repp & Barton, 1980) have been reported. The negative findings suggested weaknesses in program implementation rather than flaws in the actual program design. Relatively few studies have examined resident growth by adaptive level and those that have did not look at repeated measures across time (Lemanowicz et al., 1980).

The present study attempted to systematically explore the effects of the ICF/MR program at Sunland by looking at large numbers of subjects, several variables, and repeated measurements over several years. Subjective observation and impressions of the ICF/MR program have suggested that the quality of residents' lives has indeed improved, but continued investment of effort and expense requires systematic study and empirical evidence.

Expected Results

Subjects living in Sunland ICF/MR training units should exhibit greater adaptive level gains as measured by an instrument of

developmental growth (the Vineland Social Maturity Scale) than residents of more traditional living units. Among profoundly retarded clients, those with fewer major physical handicaps can be expected to show higher gain scores than those with two or more handicaps. Non-ICF/MR subjects should show more progress during the year following unitization than during the period prior to it due to improved staffing and programming services. Among ICF/MR clients, a relationship can be expected between adaptive growth and age at institutionalization, years lived in the traditional institutional atmosphere, and years spent in the ICF/MR program.

The review of the literature which follows will examine the history of treatment of the mentally retarded. Current intervention strategies and probable factors which influence their effectiveness will be discussed.

CHAPTER II REVIEW OF THE LITERATURE

A great deal of research has been conducted on the etiology and treatment of mental retardation. Chapter II examines the literature related to this study beginning with a review of the historical treatment of the mentally retarded. The effects of variables such as institution size, resident's pre-institutional history, length of institutionalization, staff-client ratio, and staff behavior are examined. Finally, the trend toward moving the retarded into the community is discussed as well as several factors which may influence the success of such placements.

Definition and Diagnosis of Mental Retardation

The ability to function in one's environment is dependent on both intellectual and adaptive levels. This interaction is reflected in the American Association of Mental Deficiency (AAMD) definition of mental retardation: "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested in the developmental period" (Grossman, 1977, p. 5).

To be classified as mentally retarded, therefore, an individual must score two or more standard deviations below the mean (in the

lower 2% of the entire population) on standardized intelligence tests, exhibit adaptive behavior which "will fail to meet the standards of personal independence and social responsibility expected of persons of similar age and cultural background," and manifest the condition before age nineteen (Anderson, 1981, p. 715).

While formulation of this definition ended much of the guesswork previously involved in the diagnosis of retardation, classification and labeling of an individual as mentally retarded remain a less than perfect endeavor.

Classification of persons as mentally retarded, although not precise, does serve the purpose of permitting service delivery to a defined population. There is a positive correlation between agreement on the operationalized definition of a special education population and the availability of services for that particular population (Sabatino, 1981). In other words, when there is general agreement on a need, i.e., retardation, that need is more likely to be addressed.

Levels of retardation are defined as follows (Grossman, 1977):

1. Mild: This is a term used to describe the degree of mental retardation present when intelligence testing scores range 2-3 standard deviations below the norm (52-67 on the Stanford-Binet and 55-69 on the Wechsler scales); many educable retarded individuals function at this level; such children usually can master basic academic skills while adults at this level may maintain themselves independently or semi-independently in the community; they are fixated at Piaget's concrete operations stage.
2. Moderate: IQ scores range 3-4 standard deviations below the norm (36-51 on Stanford-Binet and 40-54 on Wechsler); many trainable

individuals function at this level; such persons usually can learn self-help, communication, social and simple occupational skills but only limited academic or vocational skills; they are fixated at Piaget's pre-operational intuitive stage.

3. Severe: IQ scores range 4-5 standard deviations below the norm (20-35 on Stanford-Binet and 25-39 on Wechsler); such persons require continuing and close supervision but may perform self-help and simple work tasks under supervision, sometimes called dependent retarded; they are fixated at Piaget's (upper level) sensorimotor stage.

4. Profound: IQ scores range more than 5 standard deviations below the norm (19 and below on Stanford-Binet and 24 and below on Wechsler); such persons require continuing and close supervision but some may be able to perform simple self-help tasks; profoundly retarded persons often have other handicaps and require total life support systems for maintenance; they are fixated at Piaget's (lower level) sensorimotor stage.

History

Thirteenth century England distinguished between the classes of "born fool" and "lunatic" (Anderson, 1981). In the nineteenth century, these same two classes of retarded were known as "idiots" and "imbeciles." Probably the first written definition of mental retardation is credited to Esquirol in 1845:

idiocy . . . a condition in which the intellectual faculties are never manifested, or have never been developed sufficiently to enable the idiot to acquire such amount of knowledge as persons of his own age and placed in similar circumstances with himself are capable of receiving. (Anderson, 1981, p. 716)

While an admirable attempt, this definition classified people as retarded if they had any one of a wide range of handicaps including epilepsy, emotional disturbances, and deafness.

The Idiots Act of 1886 (Anderson, 1981) discriminated between institutionalized "idiots" and "imbeciles." Labels such as Idiot, Imbecile, and Moron persisted into the 1960's. Value labels such as these may have contributed to the poor care generally available as well as being a product of the philosophy that allowed such abysmal care. In the nineteenth century, Itard worked with the "wild boy of Aveyron" and was able to improve his condition somewhat, in spite of the prevailing wisdom that idiocy was an incurable and chronic disease. In 1905 Binet and Simon developed the first standardized method of consistent classification so that educable retarded children could receive special training. Community-based services came into existence in the mid-1950's and John F. Kennedy established the President's Committee on Mental Retardation in the early 1960's. Section 504 of the Rehabilitation Act of 1973 and P.L. 94-142, the Education of All Handicapped Children Act of 1975, mandate a free and appropriate education in the least restrictive program for all handicapped children (Turnbull & Turnbull, 1978).

Demographic Data Collection

Numerous surveys have collected information on the incidence and characteristics of the retarded population in this country. Methodology has been varied and the data obtained have often been unreliable, limiting the information base available for policy decisions.

The first demographic data gathered on the population of mentally retarded persons in the United States were drawn from the census of 1850 (Lakin et al., 1982). Efforts centered on counting the number of "idiotic" and "feeble-minded" persons, as well as other "defective, dependent, and delinquent classes." Census methodology was poor at best, but it did signal some interest on the part of the federal government in an important segment of its population. Initial surveys attempted to count persons in the community as well as in institutions but the data obtained were so unreliable that surveys after 1902 were restricted to institutions. From 1926 to 1932, authorization was made for data collection on "inmates in penal institutions and of institutions for the care of the mentally diseased and of feeble-minded and epileptics." Various government agencies have been assigned the task over the years and the labels have changed from "moron," "imbecile," and "idiot" to "mild," "moderate," and "severe-profound." Data collection continues and the interest of the federal government in the developmentally delayed population has waxed and waned depending on the political bent of the administration in power and the state of the national economy.

Normalization

Emphasis on deinstitutionalization and normalization as well as an overall decrease in numbers of school age children has resulted in greatly diminishing numbers of people living in institutions for the mentally retarded (Lakin et al., 1982). Normalization philosophy

was first formally addressed in the 1959 Danish Mental Retardation Act (MacEachron, 1983) which sought "to create an existence for the mentally retarded as close to normal living conditions as possible" (p. 2). The United States has adopted this approach and made it the primary goal of the Joint Commission on Accreditation of Hospitals (JCAH): "The facility *shall* accept and implement the principle of normalization, defined as the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible, taking into account local and subcultural differences" (p. 3). As MacEachron points out, the expectation of the Americans was that normalized behavior would be a direct result of placing mentally retarded persons into a normalized environment.

Exactly what constitutes a normalized environment has not been determined, however, and Lakin et al. (1982) report that the number of readmissions to public residential facilities has exceeded the number of first admissions since 1978.

Care of the mentally retarded has become big business. The cost of maintaining a public institution has risen dramatically since 1970. According to Lakin et al. (1982), the mean "real cost" (cost converted to 1967 dollars) of institutional care increased from approximately \$4,000 per resident per year in 1970 to over \$10,000 in 1980. Reasons for the increase include both overall improvements in the quality of care given as well as the need for more intensive care by the severely mentally, behaviorally, or medically handicapped individuals still remaining in the institutions.

Institutionalization versus Deinstitutionalization

To institutionalize or not to institutionalize? This is a timely issue and an important one, one which involves hope, guilt, money, and some very strong feelings: "A long time ago, someone once created a now-famous motto for an institution for the mentally retarded, 'Happiness First, All Else Will Follow' . . . an accurate motto for today might be, 'Business First, and What Else Is There?'" (Blatt, 1981, p. xiii).

The prevailing opinion until recently has been to recommend institutionalization as soon as a child is diagnosed as retarded, often on the first day after birth for those with easily recognizable symptoms such as Down's Syndrome. The rationale has been that an abnormal child living at home will have a detrimental effect on any siblings and quite possibly destroy the family.

Additionally, it has been argued that a large, centralized institution can provide a greater variety and quality of services for the residents than can a small home. Large institutions, however, too often become mere "warehouses" for the unfortunate people living there. Jordan (1985) cited Jerry Rivers' (Geraldo Rivera of ABC's popular news-magazine show, "20/20") daring 1972 expose which graphically illustrated this type of "care." He and his crew strapped on cameras and ran through the wards at Willowbrook State School in New York (now known as the Staten Island Developmental Center). The resulting film showed what was truly a snakepit: "conditions more fitting for a concentration camp than a hospital. Images of helpless children, ostensibly in New York's

benevolent care, but in fact completely neglected, wallowing in filth and ravaged by one of any number of diseases" (Jordan, 1985, p. 70). Speaking from personal experience, there is an unmistakable and unforgettable stench that one finds in such a ward, a combination of drool, urine, and feces; and a sound of misery and total isolation. Ward attendants in such places are often caring people but usually underpaid, overworked, and therefore relatively powerless to effect any changes in such an environment.

Duly shocked by such living conditions, public opinion swung to the extreme in the 1960's (Baroff, 1980) and cried for "normalization," declaring that all institutions are terrible and inhumane places and that the only good placement is in the community in a normalized environment, where "mentally retarded persons should share the cultural patterns and have the advantages offered to others" (Tjosvold & Tjosvold, 1983, p. 28). The case of the Pennsylvania Association for Retarded Children (PARC v. Commonwealth of Pennsylvania, 1971) established the rights of mentally retarded children to equal educational opportunity:

It is the Commonwealth's obligation to place each mentally retarded child in a free, public program of education and training appropriate to the child's capacity . . . placement in a regular public school class is preferable to placement in . . . any other type of program of education and training. (Meyen, 1978, p. 89)

The battle between pro- and anti-institutionalization proponents rages, a battle with client welfare, parental emotions, and cost as the elements. The "Community and Family Living Amendments of 1983" would "phase out, over a 10 year period, all residential facilities

for the mentally retarded (institutions and other ICF/MR nursing homes) of 25 residents or more throughout . . . the United States. Medicaid (Title 19) funding and residents would be transferred to community facilities of 15 residents or less" (Sharp & Polson, 1984, p. 1). This legislation was initiated in 1982 by the National Association for Retarded Citizens' resolution that "all people regardless of the severity of their disabilities, are entitled to community living" (Sharp & Polson, 1984, p. 2). Such strong anti-institution sentiment is not uncommon, as the following piece by Blatt (1981) illustrates:

In the special world of institutions,
One learns the rules only by breaking them,
And is happy if he's not depressed,
With full control when not unhinged,
For he's alive just because he's not dead,
But dead while he lives. (p. 99)

Florida succeeded in reducing the population in its six state retardation institutions by 47% from 1970 to 1981, with a resultant census of 3,356 residents (AFSCME, 1984). Deinstitutionalization has not succeeded as well as it might, however, and client distress, abuse, and death have resulted. Some clients have been unwittingly moved to residences of questionable quality. One nursing home chain is under investigation in at least five states and allegedly has ties with organized crime. Some homes have been closed because of abuse to the residents, such as the Jesus Loves You Home for Boys (AFSCME, 1984). Other residences have been established with the best of intentions but staffed by people with little or no retardation experience and unequipped to address specialized health and behavioral needs. Community

placements are showing an improvement in quality as the state works through these problems. It is clear, though, that a very real danger exists when deinstitutionalization becomes a goal to be achieved at all costs.

Intermediate Care Facilities

The ICF/MR program attempts to provide a healthy, growth-oriented environment within the institutional setting. Witt (1981) studied clients in an ICF/MR facility and found significant increases in adaptive level scores approximately ten months after placement, especially in the areas of self-help, socialization (development of peer interaction), and occupation (manipulation of objects and self-initiation of play activities). Bedinger and Miles (1982) found similar results in a pilot study which compared ICF/MR clients in two facilities at Sunland with clients living in non-ICF/MR cottages at the same institution. Ellison (1983) found significant gains but an erratic pattern of growth when thirty-two profoundly retarded women were moved from a custodial to an ICF/MR unit.

Bible and Sneed (1976) question the value of ICF/MR. They observed training in a facility before and after a pre-announced accreditation survey and found an average of only 29.9% and 32.5% of scheduled training sessions actually conducted on two wards during non-survey conditions. During the survey, however, 85.5% and 84.5% of training sessions were run as scheduled. Bible and Sneed suggest that surveys should be conducted randomly and not announced, and wonder whether

ICF/MR is a cost-effective program or merely a way of providing better custodial care for clients. Similar findings were reported by Repp and Barton (1980).

Conroy and Bradley (1981) found that "factors that appear to be related to client development within the institution are the amount of day program, the degree of individualized treatment (as opposed to regimentation in groups) and the number of medications given daily (the more medication, the less growth). Whether or not a cottage is ICF/MR certified is not related to client development" (p. 3).

It is apparent that the ICF/MR program is subject to the same caveat as deinstitutionalization: Better physical plant and budget do not necessarily insure better resident care and training. As with any approach to treating the mentally retarded, both positive and negative results have been found. Conflicting findings and a paucity of literature indicate a need for further review of the ICF/MR program.

Community Placement versus Institutional Care

Results of research on the desirability of community placement have often been contradictory and offer evidence to support both sides of the issue. For instance, Balla et al. (1974) reviewed studies of institutionalized children which found decrements in language and ability to abstract, conceptualize emotional continua, discriminate or form a learning set. Other studies reviewed by them, however, reported increases in problem solving autonomy and IQ as well as a normal

developmental sequence of psychological growth, although at less than one-half that which would be expected based on initial IQ scores.

The Pennhurst decision (Halderman v. Pennhurst State School and Hospital et al., 1978) declared that "mentally retarded persons residing in Pennhurst, a state-operated facility in Spring City, Pennsylvania, had a right to receive services in the least restrictive setting appropriate to their needs, and that these rights had been abridged by their being institutionalized" (Crunk, 1982, p. 1). The Federal Court claimed that clients institutionalized at Pennhurst had regressed. Follow-up of thirty-one mainly severely and profoundly retarded Pennhurst clients moved into the community after the court order suggested that their independent functioning skills had shown considerable improvement although causal factors could not be isolated (Conroy et al., 1980).

Conroy and Bradley (1981) summarized five-year longitudinal follow-up data for clients still remaining at Pennhurst after the deinstitutionalization order and for those who had been moved to the community. Rather than regressing, institutionalized clients actually gained a "very slight amount" in self-care skills.

What becomes evident is that the question of community versus institutional placement is not a black and white issue as so many would choose to believe. The assumption that institutions for the retarded are homogeneous environments and that the needs of all mentally retarded persons are the same is erroneous. Evidence, as well as common sense, indicates that not every institution is the same, nor is each community placement, nor each client or staff person.

Eyman and Borthwick (1980) found that residents of institutions are generally more severely retarded and exhibit more problematic behaviors than do residents in community placements. As a result of selective admission and release policies, institutional populations are skewed toward the lower level of functioning. To say that community placement is necessarily the best placement for all mentally retarded persons is to make the assumption that such facilities are equipped with the physical plant and staff to handle such a problematic population. These assumptions have not been met, nor are many community facilities willing to accept profoundly retarded clients or those who have recurrent behavior problems.

Factors such as institution size, pre-institutional history of clients, staff-client ratio, and staff attitudes affect resident adjustment and development in any placement. These variables will be examined to see how each relates to the question of optimal placement for the developmentally delayed.

Institution Size

Are large institutions depersonalizing or do they provide a wider range of services than are available in the community? The assumption has been that only a small community residence can offer an acceptable and humane quality of life. The courts have ruled that mentally retarded persons have "the right to the least restrictive conditions necessary" (Wyatt v. Stickney et al., 1972) and the right to live in the "least restrictive setting appropriate to their needs, and that

these rights had been abridged by their being institutionalized" (W.A. Crunk, communication about Broderick decision, February 9, 1982).

Yet as recently as 1975, Edgerton found that most of the "board and care" facilities (group homes) he studied in California were "closed, ghetto-like places" which lacked most services and where "the residents . . . are given to understand, in no uncertain terms, that they can hope for nothing different in the future. . . . For most mentally retarded people in this system . . . the little institutions where they now reside appear to be no better than the large ones from which they came, and some are manifestly worse" (pp. 130-131). As cited in Sandler and Thurman (1981), Butler and Bjaanes described many of the community facilities they studied as being "socially isolated total institutions within the community" (p. 392). Smaller is not necessarily better and in fact can be much worse (O'Connor, 1976).

A "collaboration" rather than "control" approach should "encourage social support, mutual assistance, and coordination of efforts that strengthen social skills and learning of most cognitive skills" for residents (Tjosvold & Tjosvold, 1983, p. 36). Institutions, however, stress obedience, conformity to routine, and a lack of conflict with peers (Dentler & Mackler, 1961). Instead of fostering social and emotional development, institutional social deprivation encourages residents to be dependent and suspicious (Zigler, 1978), to deceive and manipulate staff members (Braginsky & Braginsky, 1971), and to feel helpless (DeVellis, 1977; Veit et al., 1976).

McCormick et al. (1975) studied institutions in this country as well as in Scandinavia, a country which has a reputation for enlightened

care of the mentally retarded. They found, predictably, that large facilities in both countries provide the most institution-oriented and depersonalized placements but also that Scandinavian practices are generally more resident-oriented, particularly in the severe units. The authors offered the following explanations for the difference in care between the two countries: 1) Scandinavia's policy of normalization has attempted to provide a life for its retarded that approximates cultural norms as closely as possible, including living environment, social behavior, and freedom of choice; 2) child care is a valued profession and requires a three-year child developmental training program involving both class work and hands-on training; and 3) the best client-staff ratios were found in the severe units. Overall, though, care practices in both countries were determined by the size of the institution and not significantly affected by cost per resident, number of aides, or number of professionals per resident.

MacEachron (1983) found an increase in adaptive behavior one year after residents had moved into new, normalized cottages at a state institution. However, the institution was applying for federal funding and so the newer cottages also provided more programming and training for the residents than did the control cottages. Whether the more normalized environment would have been significant in the absence of the programming requirements is doubtful.

Balla et al. (1974) found response to institutionalization to be differentially affected by characteristics such as residents' preinstitutional history, sex, diagnosis, and the particular institutional environment. Out of five social skills variables examined,

responsiveness to social reinforcement was the only factor found to be significant. Residents were more motivated for social reinforcement (as measured by total time on task when performance was verbally praised by the experimenter) in the institution that had subjectively been rated by the authors as providing the most attention to the residents. They question their own finding on the basis of previous research (Green & Zigler, 1962; Stevenson & Fahel, 1961; Zigler, 1961, 1963; Zigler & Balla, 1972; Zigler et al., 1968) which suggests that a socially deprived environment encourages heightened motivation for social reinforcement. The authors conclude that their subjective opinion of which institution provided the most attention to residents was incorrect since those residents should not have demonstrated the most desire for social contact. This interpretation is questionable. Research has shown that social behavior can be reinforced or extinguished (Mayhew et al., 1978). Behavior theory predicts that an institution which provides attention to residents will have a high rate of reinforced attention-seeking responses. However, despite the tenuous nature of their decreased attention/social reinforcement hypothesis and a questionable definition of social motivation, Balla et al.'s conclusion that smaller is not necessarily better when comparing institution size is well supported.

Bedner (1974) found that smaller homes foster interpersonal relationships but Bell (1974) disagrees, stating that friendship between residents is more likely to occur in larger, more diverse homes where residents have a better chance of finding a friend who shares their interests. Landesman-Dwyer et al. (1980) found that staff-resident

interactions did not vary with home size but that the most resident-resident interactions occurred in medium-size homes of nine to seventeen residents and the least in small homes of six to eight residents. Residents of large homes (eighteen to twenty residents) were most likely to have a "best friend." Effects of group home size were secondary to variables such as geographic location of the home, heterogeneity of the residents' backgrounds, and average resident age.

Rotegard et al. (1983) found smaller facilities (less than sixteen residents) to be more homelike than larger settings, and residents in homes of five to eight persons most encouraged to be autonomous and active. It must be noted, however, that the larger facilities had lower level, more handicapped residents and less satisfied staff members. The authors follow a tautological line of reasoning when they say that higher level, higher functioning clients are more autonomous and active.

In his review of the literature, Baroff (1980) suggests that size differences are only important when large, as when comparing a large institution to a small group home. Within the type of placement (large central institutions, large and small regional centers, and group homes), actual size has not been shown to be significant. Seven out of the eight studies reviewed by Baroff suggest that smaller settings provide more advantages for residents. The eighth study found no differences. Community settings may provide more individualized experience and opportunities for residents, but Eyman et al. (1975) found that institutional residents enrolled in training programs showed significantly greater improvement than residents who received

standard institutional care or former residents who had moved to community homes that did not provide training.

Pre-Institutional History of Residents

In their 2.5 year longitudinal study of the effects of institutionalization on retarded children, Balla et al. (1974) determined that preinstitutional social deprivation can significantly affect later development, as measured by IQ and social responsiveness. While no overall IQ effects were noted, residents of two of the institutions studied experienced significant changes in IQ after placement. The IQ decrease of children who had experienced low degrees of preinstitutional social deprivation suggests that the institutional setting is less reinforcing in general to children who have had richer pre-institutional experience. The authors suggest that these children exhibit behaviors that compete with the motive to be correct during the testing situation and therefore obtain lower IQ scores. IQ decreases in children who experienced high amounts of social deprivation prior to placement are attributed to their motivation to escape the testing situation. The authors conclude that development after institutionalization is a function of both the particular placement as well as the resident's pre-institutional history of deprivation. The subjectively rated deprivation levels of the various institutions studied must be taken into account when interpreting the authors' findings.

In their review of the literature Lemanowicz et al. (1980) found that residents socially deprived before institutionalization experienced

increases in IQ and social responsiveness after placement. The rate of growth did not remain steady but lessened as the length of time in the institution increased. Individuals who have a prior history of "emotional instability" or "past liability" can be expected to respond poorly to change (Cohen et al., 1977).

Length of Deinstitutionalization

Clients placed in community homes exhibited more gains in their adaptive level after one year in the community, especially in their communication skills, than did controls who had remained in the institution (Schroeder & Henes, 1978). Gains were most evident shortly after placement and tended to stabilize with time. The authors question whether the environment aided in the acquisition of new skills or merely encouraged more use of already-existing skills, adding that "institutional staff often remark at the amazing disappearance of the 'institutional shuffle' when residents leave campus" (p. 148). While Macy (1977) found no clear trend between length of time in community placement and level of independent functioning, his results did support Coffman and Harris' (1980) contention of an initial "honeymoon" period after movement to the community followed by an extended adjustment period.

Institutional Factors

In addition to the environmental factors already discussed, researchers have examined institutionalized residents' response

to the number of staff assigned to a ward, staff attitudes, and behavior.

Staff-Client Ratio

One or two ward attendants admittedly have a difficult time caring for a unit of fifteen to twenty clients. If the usual duties of house-keeping and laundry are also their responsibilities, attendants' time or motivation for positive interactions, not to mention training, is limited. The logical solution then is to assign more people to the ward. Unfortunately, or perhaps fortunately since more staff means more expense, the solution is not all that easy.

In their 1975 study, McCormick et al. examined staff-client ratio in terms of both number of aides and number of professionals per resident and found neither ratio to be predictive of care practices. The Scandinavian homes studied generally had twice as many clients per staff member as did the American homes (U.S.: seven to twenty-four clients supervised by one live-in couple; Scandinavia: fifteen to fifty-seven clients supervised by one live-in couple) but provided the same services. Merely increasing the number of staff does not insure better care for residents. Scandinavian staff utilization practices, normalization philosophy, and respect for and training of child care personnel demand more scrutiny if optimal institutional care is to be provided.

Harris et al. (1974) time sampled a ward at a state institution and found that increasing the number of aides had no effect on the

amount of formal training and proportion of positive attention given the residents. Neither have low staff-resident ratios been shown to increase resident adaptive behavior levels (Grant & Moores, 1977). Harris et al. did find that aide behavior was more nurturant and pleasant when fewer residents were present and suggest that assigning an aide to a specific group of clients would be more effective than merely increasing numbers of staff.

Blindert (1975) counted an average of less than one staff-resident interaction per 10 minutes when one employee was present on the ward. An increased ratio of 2.4 staff to 7.6 residents still resulted in less than one (0.58) teaching and learning and only 1.94 total staff-resident interactions per client. Increasing the number of staff resulted in more staff-staff discussions about extracurricular topics rather than acceptable staff-resident interaction levels.

Staff Behavior and Attitude

What are staff doing while they are on duty? Less than 1% of their time is spent in positive interactions with residents (Landesman-Dwyer et al., 1980). Thormahlen's 1965 study (cited in Dailey et al., 1974) found that aides spent 2% of their time training self-care skills and 36% encouraging dependency behaviors. Aggressive and antisocial residents receive a large proportion of staff attention (Grant & Moores, 1977) while residents with higher levels of independence and adaptive behavior and lower levels of maladaptive behavior receive a greater proportion of interactions that "promote warmth or positive development." In order to encourage staff

interest in each resident, regardless of perceived client attractiveness or problematic behaviors, Grant and Moores suggest reorganizing units so that each staff member will be responsible for a definite group of residents.

Blindert (1975) found "correct" attitudes in the staff he observed, negated unfortunately by their focus on other staff rather than on training and client-oriented interactions.

Mayhew et al. (1978) conducted an ABAB reversal study in which attention was alternately given to and withheld from severe-profound girls in a ward dayroom. Social behavior was found to be dependent on the experimenter's behavior, suggesting that residents who exhibit little social behavior may be under a permanent extinction schedule instead of lacking social skills as has usually been thought. Observation of the ward six months after the study showed that staff continued to exhibit resident-directed social actions only about 10% of the time. Seventy-five percent of their time was devoted to custodial and housekeeping duties. Warren and Mondy (1971) observed that aides failed to respond to appropriate resident behavior 75-80% of the time. Veit et al. (1976) found that aides ignored 30% of all resident-initiated interactions, and any interactions that did occur were mainly neutral. Staff members designated and trained as behavior modifiers spent no more time training than did regular aides (Gardner & Giampa, 1971).

Dailey et al. (1974) found that aides spent 51.2% of their time interacting with clients, but that this occupied only 4.2% of the "average" resident's time and was mainly directed toward those

residents perceived as "attractive, likable and intellectually competent" (p. 590). This finding agrees with Veit's (1973) that 24% of the residents received 57% of all attention and further supports the hypothesis that most residents are on an inadvertent extinction schedule.

Environmental setting can influence staff attitudes (Tognoli et al., 1978). Egocentric behaviors emitted in a ward dayroom (sitting alone, watching TV) were rated as being more active by ward attendants than by psychologists and therapists. Administrative personnel and ward attendants showed no significant difference in their ratings of dayroom versus playroom behaviors, the administrators having little day-to-day contact and the attendants stationing themselves in an office away from the residents. Tognoli et al. express concern that differing perceptions of resident behavior may result in programs not being run as designated since the programs are often written by therapists but implemented by aides.

Summary

As the literature has shown, life in an institution can be either positive or negative for the residents. Size alone is not important; factors such as preinstitutional history and staff number and characteristics influence resident development.

Conroy and Lemanowicz (1981) have suggested several ways to encourage resident growth in institutions:

1. Increase day program hours away from the sleeping area;

2. Increase the individualized treatment of clients as opposed to treatment "en masse" and rigid routines that everyone must follow;
3. Review and decrease medications wherever experienced physicians deem it safe;
4. Beyond these steps, other actions (such as increasing staff ratio, getting ICF/MR certification, or meeting the AC/MRDD standards for programming) are likely to have relatively little effect.

Both research and emotion play a part in resolving the question of whether or not community placement is preferable to institutionalization. As the above review of the literature has shown, this is a simplistic approach to a complex problem and has resulted in a rush to deinstitutionalize with very tenuous research support. The concern should instead be one of custodial versus therapeutic care (Kleinberg & Galligan, 1983), and of the individual characteristics of each client and potential community placement (Gibson & Fields, 1983). Factors such as size of placement, number of staff, and budget seem to be foils if not implemented in coordination with other community or physical plan characteristics: It is what is happening inside the placement that the literature says is critical.

Success of Community Placement

Movement of retarded persons from institutional settings into the community is not a simple matter for the persons involved and, in fact, can become very difficult for several reasons. Community placements made between 1960 and 1965 had a failure rate of 52% compared with

only 40% failure for the period 1941-1965 (Gibson & Fields, 1983). Examination of successful placements since 1929 reveals a negative correlation between success rate and budget, staffing and presumed quality of programs; i.e., success rates were highest during poor resource and funding years (and when higher level, well-behaved residents were being placed). Gibson and Fields suggest that the current decline in success rate is due to changes in institutional intake policy and release mandates. Institutional admissions are presently restricted mainly to the more handicapped individuals, and the pool of residents who may be considered for community placement is composed of physically, emotionally, and behaviorally problematic individuals who may have already failed in the community or who have never been considered appropriate for placement.

Problems in Community Placements

Group living and foster homes have the potential for providing a truly homelike, normalized placement for mentally retarded persons. The fact remains, though, that since 1978 the number of readmissions to public residential facilities has exceeded the number of first admissions (Lakin et al., 1982). In the present author's experience, a disappointingly large number of clients have returned to Sunland from community placement, often in emotional distress and on heavy doses of emergency psychotropic medication (drugs which influence affective, emotional, and behavioral states). For some clients, in fact, this writer has found that the institution appears to be the

least restrictive environment or at least one in which they experience less severe emotional stress.

Transition shock (transitional adjustment) should be expected when a mentally retarded person experiences a major life change, especially if the change is not voluntary or understood by the resident (Macy, 1983). Response to community placement, while an individual matter, is additionally influenced by level of retardation (Cohen et al., 1977). Higher functioning persons tend to become depressed and withdrawn while lower functioning persons exhibit more behavior, both appropriate and inappropriate.

Residents have a great deal of personal freedom at Sunland. Most live in unlocked cottages, go outside at will to visit with others or play, and have access to the Center bank and store. Movies and dances are frequent, as are field trips into the community. In addition to a degree of independence, Sunland also provides a great deal of structure and behavioral control for the clients. Career staff have known many of the residents since their placement at the Center many years ago.

Movement to a small community setting often requires a great deal of adjustment for a retarded person who has been used to a very different type of lifestyle and who may accept change with difficulty. Community placements are often physically attractive but may have locked doors because of close proximity to a highway. Clients who try to go outside as they have been used to doing at the institution have been branded behavior problems. Unusual behaviors emitted while trying to adapt to their new home have been labeled schizophrenic.

Motivated and empathic staff working in community placements often lack the experience necessary to deal successfully with problematic clients. The structure provided in the community is frequently loose, the staff have no background knowledge of the particular client, and inappropriate behaviors may quickly increase in frequency. Communication between community staff and Sunland has been poor in that often the first indication Sunland staff have had of a problem is the return of a client to the Center, frequently after the client had caused a fairly serious disturbance in the community and required psychiatric and/or crisis intervention.

The majority of clients who adjust successfully to the community are very happy there (Sandler & Thurman, 1981) but more than half of those who return to the institution express a definite preference for institutional life. One client was happy to return because "the house manager beat me up when I fed the dogs too much. I couldn't go anywhere. I had to stay in the house. Not allowed to open doors [sic]." (p. 248). Obviously, one cannot say that community placement per se is superior to life in an institution.

Factors Involved in Successful Community Placement

Many community placements provide excellent care for their residents but exactly what constitutes a successful environment has not been determined. Sandler and Thurman (1981) found a lack of empirical evidence in the literature and concluded that "philosophical/legal/political mandates for community placement have continued to provide the major impetus for the community placement movement" (p. 245).

Environmental factors

Staff expectations affect resident behavior. Placement in a community setting may permit use of social, domestic, and communication skills that have been previously unneeded or unreinforced (Kleinberg & Galligan, 1983). Campbell (1971), however, found that clients living in a community placement showed no progress, probably because the staff did not expect them to do things for themselves. Clients in an enriched or training community environment show substantial gains as compared with residents who remain in an institution which does not provide any special programming or training (Tizard, 1964; Close, 1977). By the same token, clients in an institution who receive special training are more likely to show progress and continue to learn than are clients who are moved to a community setting but receive no special training (Eyman et al., 1975).

Bjaanes and Butler (1974) studied several board and care facilities (thirty to fifty residents) and home care facilities (four to six residents) and found that the board and care facilities achieved more closely the objectives of fostering normalization and developing social competence. More social interactions and independent behavior were encouraged in the board and care facilities. The authors suggest that the staff-resident ratio of one to seventeen provided for much less supervision and structure than did the home care facility ratio of one to five and permitted more social interactions and independent behavior to occur. The main finding of the study, however, was the importance of the amount of community exposure afforded the residents. Clients at the board and care facilities lived within walking distance

of movies, buses, parks, and a mall. They were basically free to go where they wanted and were more likely to attempt to conceal their retardation and history of institutionalization than were the clients in the home care placements, which were located in suburban areas but not within walking distance of any facilities or entertainment.

Hull and Thompson (1980) investigated further the question of optimizing adaptive functioning in a community placement through manipulation of the environment. In agreement with other research discussed, the two most important environmental factors identified in the study were the location of the residence (accessibility to and from the residence and adequacy of transportation facilities) and the promotion of socially integrated vocational, educational, recreational, and social activities. Other important factors were the extent to which the residents were helped to achieve culturally appropriate appearance and behavior, and whether the residents were treated by the staff with courtesy and respect. Interestingly, quality of physical setting was slightly negatively related to adaptive functioning, i.e., residents in homes with somewhat poorer physical plant demonstrated slightly greater Community Awareness (transportation, budgeting, shopping, cooking, and leisure skills). The authors do not attempt to explain this finding, but do suggest that merely improving the physical appearance of a residence is not sufficient to insure successful community placement. They point out that their findings are based on cross-sectional research and that longitudinal studies are necessary to further isolate the factors most important for successful client adaptation to the community.

Individual factors

While environmental and staff characteristics are important in helping an individual adjust to a new home, pre-move interventions significantly reduce transition shock and thereby enhance the probability of successful adjustment. In the present emphasis on decreasing institutional census and moving residents to a (hopefully) more normalized, humane environment, "lost is the realization that the new, cleaner environment with its additional services, higher staffing levels, greater individual space and more personal attention represent dramatic changes that may be perceived as a threat and therefore create stress" (Macy, 1983, p. 26).

The literature suggests some strategies for preparing institutional residents for community placement: desensitization to the new neighborhood culminating in visits to the new home, a process used successfully with four mildly retarded schizophrenics (Dondey, 1982); slowly increasing demands on new residents (Harris et al., 1981); instruction for community staff in the institutional teaching methods and daily schedules (Coffman & Harris, 1980); and involving residents by having them construct photo albums of both the institution and their new placement and peers (Williams, 1982).

The issue of institutional versus community placement is a misleading attempt to find an easy answer to a complex problem. Research studies have so far found answers that satisfy proponents of both institutionalization as well as deinstitutionalization but there is substantial evidence that a complex set of factors and interactions is involved. To say that one setting is preferable to another is to

ignore the individual variables involved in each placement such as physical plant, number of residents, staff-client ratio, staff attitudes, availability of training and community resources, and client individual differences.

The "answer" appears to lie in following a more individualized approach that takes each person's level of functioning and personality into account in addition to environmental variables. Ellis et al. (1981) suggest training those clients who show improvement and working toward an end goal of improving quality of life through the application of realistic individualized goals for each individual rather than enforcing "across-the-board, formal, ritualistic training."

Institutions work with large numbers of residents, a sizable number of whom are non-communicative. Under such conditions, it is sometimes too easy to forget that these clients are caring, feeling individuals. Further research is necessary to determine exactly which conditions are most likely to provide a dignified life for the developmentally disabled. The present study will look at some of those conditions.

CHAPTER III METHODOLOGY

The underlying hypothesis of the present research was that retarded persons living in a large state institution will show a significant increase in adaptive skill level when placed in the structured training environment of an Intermediate Care Facility for the Mentally Retarded (ICF/MR). Conversely, persons living in a more traditional custodial setting at the same institution (non-ICF/MR) will show little improved development over the same period of time.

Subjects

Subjects were selected from the population at Gainesville Sunland, a state institution for the developmentally delayed. The 437 subjects include all moderately retarded residents who had lived in an ICF/MR cottage for three years and severely and profoundly retarded residents who had lived in an ICF/MR cottage for at least four years as of January 1, 1984 (see Table 3-1). Less data were available for moderately retarded ICF/MR subjects because the facilities housing them had been licensed for less time than the facilities housing the severely and profoundly retarded ICF/MR subjects. All moderately, severely, and profoundly retarded residents who had lived in non-ICF/MR cottages for the corresponding period of time served as control subjects and their 1979 Social Age (SA) scores were used to correspond with

ICF/MR entry scores. All research was conducted by means of record review and subjects' names were held in confidentiality.

The 437 subjects comprised 50% of Sunland residents at the time of data collection. Mildly retarded residents living in the institution were not included because their numbers were too few to provide adequate statistical representation. Two ICF/MR cottages (N = 16) were excluded from the study because the clients living in them are extremely medically handicapped and not representative of the general population at Sunland. They require twenty-four hour nursing care and, although they receive ICF/MR programming services, many are essentially unresponsive to stimuli.

Table 3-1
Composition of Subjects by Treatment and Level of Retardation

	ICF/MR	Non-ICF/MR
Moderate	7 (2%)	58 (13%)
Severe	10 (2%)	42 (10%)
Profound	141 (32%)	179 (41%)
Total	158 (36%)	279 (64%)

Instrumentation

Intelligence Tests

IQ tests are administered to Sunland clients every three to six years depending on the client's age. IQ remains stable for most

residents except for unusual circumstances such as neurological deterioration or sudden improvement in health or behavior. The IQ obtained from each client's most recent intelligence test was used in the present study. The following five intelligence scales are commonly used at Sunland:

Cattell Infant Intelligence Scale--A test administered to infants and children aged three to thirty months, evaluates developmental status;

Bayley Scales of Infant Intelligence--A developmental status test similar to the Cattell for ages two to thirty months;

Stanford Binet--An age scale test that presents a series of tasks designed for each of several age levels ranging from age two years to superior adult. Emphasis is placed on verbal and comprehension skills, especially at the higher levels;

Leiter International Performance Scale--A non-verbal test which measures ability to match colors, shapes, and concepts;

Peabody Picture Vocabulary Test--A test for ages 2.5 to eighteen years which measures verbal and pointing skills.

The Wechsler Scales' emphasis on verbal skills makes them unsuitable for administration to most clients at Sunland. A test which has items most matched to the individual client's functioning level and on which he or she can achieve at least a basal score is administered. A ratio IQ is then calculated ($IQ = CA/MA \times 100$) rather than the standardized deviation IQ which has been normed to a particular chronological age.

Adaptive Level

The Vineland Social Maturity Scale (VSMS) was developed by Doll in 1935 (Doll, 1964) to measure normal adaptive level but is now often used with retarded populations as well. The VSMS is a 117 item, third-party interview instrument designed to assess level of functioning in self-help areas such as eating and dressing, self-direction (primarily money management), occupation (use of time), communication, locomotion, and socialization. Information is provided by someone other than the person being assessed, usually a parent or caregiver. Doll, as cited in Teagarden (1970), defined children's social maturity as "a progressive capacity for looking after themselves and for participating in those activities which lead toward ultimate independence of adults" (p. 575). The instrument measures skills present from infancy to twenty-five years and provides a Social Age (SA) and a Social Quotient (SQ). The following scale is used at Sunland to assign a level of adaptive functioning:

<u>Social Quotient</u>	<u>Classification</u>
69-83	Borderline
52-68	Mild
36-51	Moderate
20-35	Severe
1-19	Profound

The VSMS was developed to measure normal development but is widely used in institutions for the retarded to provide the measure of adaptive level necessary for the two-part AAMD definition of retardation given in Chapter I. Each client at Sunland is assessed yearly.

The VSMS has proven to be a useful tool but its reliability and validity have been questioned because of the third-party nature of the instrument. Items are scored based on the response of possibly biased and untrained observers, usually cottage staff (Kinder, 1970; Rothney, 1970). Cruikshank (1970, p. 574), however, wrote favorably of the instrument's ability to provide information on "the results of the individual's maturational interaction with his social milieu." He expressed concern about the necessity of relying on an informant but was satisfied with Doll's insistence that the VSMS be administered only by clinically trained examiners. This is the case at Sunland, where administration of the VSMS is conducted solely by trained psychologists. Teagarden (1970) also found the scale to be a useful clinical instrument.

Fromme (1974) found a positive correlation between the VSMS and Stanford-Binet ($r = .87$) and suggested that the VSMS can be used to estimate IQ for children above the age of fifty months. A correlation of .52 between the VSMS and Wechsler Intelligence Scale for Children (WISC) and the limited nature of Fromme's sample suggest only a very limited use for the VSMS as an estimate of IQ. Both Teagarden (1970) and Cruikshank (1970) say that IQ and SQ scores do not measure the same construct and may differ for the same person. Some lower-IQ individuals have advanced social skills, especially if raised in a supportive and instructional environment, whereas the problematic behaviors of some higher-IQ persons may cause their SQ to be lower than one might expect.

Doll standardized the VSMS on a sample of 620 normal individuals which consisted of ten subjects of each sex from birth to thirty years

(Furfey, 1970). Socioeconomic status was controlled by paternal occupation and all subjects lived in Vineland, New Jersey. Doll showed that SA continues to increase through adolescence and to the age of twenty-five when it stabilizes. Doll obtained a test-retest reliability of .92 for 125 subjects who were reexamined at intervals ranging from one day to nine months. Bradway, as cited in Furfey (1970), found a test-retest reliability of .94 for 144 mentally retarded individual retested at "intervals sufficiently short to preclude growth or deterioration of competence" (p. 257). Gardner and Giampa (1971) reported an interscorer reliability of .78 based on reports of two attendants for fifteen severely and profoundly retarded residents. They reported normally distributed scores and adequate differentiation within the studied population. The scores of a team of psychologists, nurse, and ward attendants who rank-ordered the same residents by estimation based on their experience with the subjects correlated .89 for the "brighter residents" (divided according to overall competence), and .62 for the "slower residents" with VSMS scores, demonstrating that the VSMS has criterion validity for classification of severely and profoundly retarded individuals.

At Sunland, the psychological staff has agreed upon the interpretation of VSMS items and uses a standard list of modifications which apply specifically to Sunland clients (e.g., a client who can move his or her own wheelchair is considered to ambulate independently; see Appendix A). Each year's VSMS score is compared with those of the previous years and any discrepancies investigated further to verify that they reflect true differences in adaptive level rather than informant/interviewer differences. The scores are considered by the psychological staff to be reliable and valid indicators of each client's

adaptive level of functioning and to accurately reflect adaptive growth or lack thereof.

Based on the author's personal experience as a psychologist at Sunland, the VSMS is an appropriate, reliable, and valid measure of adaptive functioning when the interviewer is trained in the use of the instrument and obtains accurate information from the informant. Although the VSMS has received some criticism, it meets validity criteria and is an appropriate instrument both in practice and for research. Some subjectivity (error) certainly remains due to the third-party interview format but is expected to be randomly distributed.

Hypotheses

Review of the literature and the author's experience suggested the following hypotheses:

- H₁: ICF/MR subjects will have significantly higher VSMS scores than non-ICF/MR subjects when grouped by level of retardation: moderate, severe, and profound.

It is anticipated that ICF/MR clients will make annual gains in VSMS scores while non-ICF/MR scores will remain stable.

- H₂: There will be significant differences on VSMS scores of profoundly retarded ICF/MR subjects according to their amount of physical handicap.

The presence of major physical handicaps of deafness, blindness, and non-ambulation is expected to make the acquisition of self-help and daily living skills for the profoundly retarded even more difficult than would be the case for a profoundly retarded person who has no physical disabilities. Persons who are afflicted with two or more major physical handicaps are expected to show the least progress.

- H₃: Amount of time subjects were institutionalized before ICF/MR placement will be negatively related to VSMS scores.
- H₄: Age at time of institutionalization will be positively related to VSMS scores for ICF/MR subjects.
- H₅: Number of years spent in ICF/MR will be positively related to VSMS scores.

Residents who have lived longer in the traditional, custodial atmosphere of the institution before placement in an intensive training program are expected to show less improvement than persons who have had greater exposure to the stimulating and normalizing effects of a non-institutional environment. Those who were institutionalized at an older age will presumably have had more experience in the community which should allow them to profit more from ICF/MR training. Progress should also increase as the amount of time spent in the training program increases.

Procedure

Five training and five non-training cottages composed of moderately, severely, and profoundly retarded residents (N = 178) at Gainesville Sunland were examined in a pilot study (Bedinger & Miles, 1982) and significant differences in rate of client adaptive development were found. Clients living in ICF/MR cottages showed significant overall improvement while those in non-ICF/MR cottages made little progress.

The present research expanded the pilot to include 437 Sunland residents. Subjects were grouped by level of retardation, i.e., moderate, severe, and profound, since response to training may be expected to vary among persons of different intellectual capacity. Profoundly retarded subjects were further grouped by number of major

physical handicaps. Only ICF/MR subjects were represented in this group due to movement of persons with major physical handicaps out of non-ICF/MR units into licensed units. Thirty-four (24%) of the 138 profoundly retarded subjects had at least one major handicap and nine (6%) had two or more.

Differences between groups were examined in order to evaluate the effectiveness of the ICF/MR program as a whole. Since group data give no information about a specific individual's response to training, case studies were written for twelve subjects in Facility III in order to examine individual differences (see Appendix B). Probable factors implicated in client progress or lack of progress were suggested. The ICF/MR Facility III was chosen for the case studies because the author was personally familiar with the clients' histories since 1980. Subjects were selected by sex and level of retardation so that each category is represented by two subjects, i.e., two male moderately retarded subjects, two male severely retarded subjects, and so on. Selection included subjects who have progressed in the ICF/MR program as well as some who have failed to show improvement.

Case study information was obtained through record review and observation. Consent forms were signed by each client's parent/guardian (see Appendix C).

Design and Analyses

In order to test the hypotheses a 2 x 3 factorial design was used with an n of 158 for the ICF/MR subjects and 279 for the non-ICF/MR subjects (N = 437).

A repeated measures design (ANOVA) was used to test differences between means. Specific hypotheses were then tested using Fisher's Least Significant Difference (LSD) with alpha at .05 for all tests. Since the hypotheses of interest were directional and à priori, the consequences of making a type I error would not be serious.

Correlations between Social Age and age at institutionalization, length of time institutionalized, and number of years spent in ICF/MR were calculated to determine whether any of these variables contribute to the potential success of an ICF/MR placement.

Summary

Subjects living in Intermediate Care Facility for the Mentally Retarded units at Sunland were expected to show greater improvement in adaptive level than subjects living in non-ICF/MR units at the same institution. Within each ICF/MR condition, subjects were grouped by IQ and the profoundly retarded were further grouped by number of major physical handicaps. Relationships between Social Age and length of time institutionalized before ICF/MR placement, age at institutionalization, and time spent in ICF/MR were studied. Twelve case studies examined individual differences.

Chapter IV will present the results of the statistical analyses.

CHAPTER IV RESULTS

Social Age scores obtained on the Vineland Social Maturity Scale (VSMS) were analyzed over six years to determine whether mentally retarded persons living in the Intermediate Care Facility for the Mentally Retarded (ICF/MR) training program at Gainesville Sunland made significantly more progress than did those living in traditional care units at the same facility.

Effects of ICF/MR Placement

H₁: ICF/MR subjects will have significantly higher VSMS scores than non-ICF/MR subjects when grouped by level of retardation: moderate, severe, and profound.

Results of the analyses support the hypotheses of significantly higher VSMS scores for ICF/MR subjects at all levels of retardation. Repeated measures effects and the ANOVA interaction for the moderately retarded group were significant ($F(4,252) = 7.19, p < .05$ and $F(4,252) = 5.23, p < .05$, respectively). Main effects were not significant (see Appendix D). Further analysis revealed that only the ICF/MR subjects made significant gains (Fisher's LSD $(1,2) = 3.78, p < .05$; see Figure 4-1). The control subjects showed no significant improvement either before or after unitization.

Severely retarded subjects showed significant effects for repeated measures ($F(5,250) = 7.62, p < .05$) and interaction effects ($F(5,250) =$

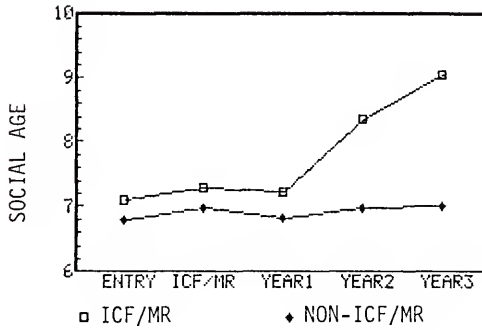


Figure 4-1. Moderately retarded subjects.

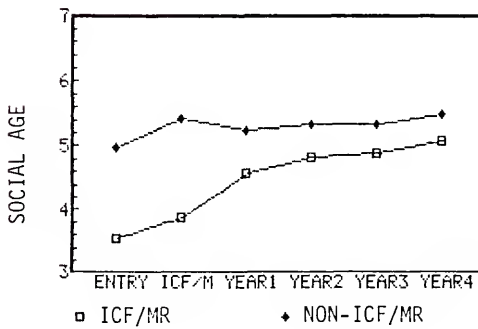


Figure 4-2. Severely retarded subjects.

3.58, $p < .05$). Main effects were not significant (see Appendix E). Only the ICF/MR subjects made progress during the four years following ICF/MR placement (Fisher's LSD (1,4) = 3.49, $p < .05$). The control subjects progressed significantly during the period between initial VSMS score at Sunland and entry to ICF/MR (1979 score for control subjects) (Fisher's LSD (1,36) = 3.58, $p < .05$) but they made no significant progress during the following years, including the post-unitization year.

All effects at the profoundly retarded level were significant (see Appendix F): main effects ($F(1,318) = 19.10$, $p < .05$); repeated measures ($F(5,1590) = 45.31$, $p < .05$); and the interaction of the two ($F(5,1590) = 16.14$, $p < .05$). Progress for both the ICF/MR and control subjects was significant during the period between their first VSMS scores at Sunland and entry to ICF/MR (1979 score for control subjects; Fisher's LSD (1,135) = 3.66, $p < .05$ and (1,173) = 6.39, $p < .05$, respectively) but only the ICF/MR subjects made significant progress during the four years following ICF/MR admission (Fisher's LSD (1,135) = 8.97, $p < .05$; see Figure 4-3). Progress for the year following unitization was significant for the control subjects (Fisher's LSD (1,173) = 3.09, $p < .05$).

The gain in Social Age scores for moderately retarded ICF/MR subjects was 1.74 (23%), for severely retarded subjects 1.19 (30%), and for profoundly retarded subjects .49 (25%).

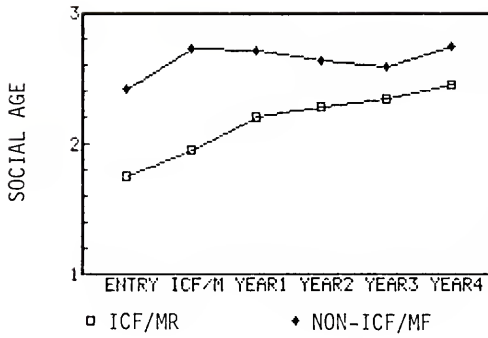


Figure 4-3. Profoundly retarded subjects.

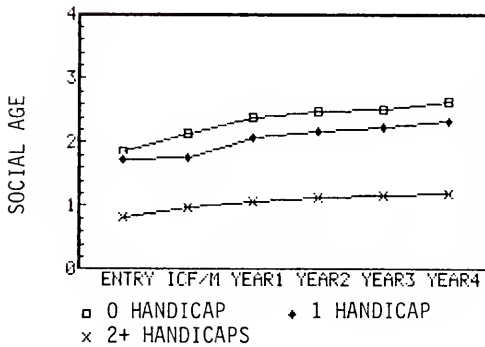


Figure 4-4. Profoundly retarded handicapped ICF/MR subjects.

Effects of Handicap Conditions

H₂: There will be significant differences on VSMS scores of profoundly retarded ICF/MR subjects according to their amount of physical handicap.

The hypothesis of differences in VSMS score based on number of major physical handicaps was supported. Significant omnibus effects (see Appendix G) were found ($F(2,135) = 11.94, p < .05$) as well as significant repeated measures effects ($F(5,675) = 22.02, p < .05$). There were no significant interaction effects. Subjects with no and with one major handicap made significant progress during the four years after their admission into ICF/MR (Fisher's LSD $(1,89) = 9.5, p < .05$ and $(1,28) = 6.28, p < .05$, respectively; see Figure 4-4), but subjects with two or more handicaps did not make significant progress. The only group that made significant progress before their placement into ICF/MR was the no handicap group (Fisher's LSD $(1,89) = 5.16, p < .05$).

After four years in ICF/MR, profoundly retarded subjects who had no major handicaps showed a SA gain of .5 (23%); subjects with one major handicap gained .55 (31%); and subjects with two or more major physical handicaps gained .24 (25%), compared with the overall gain of .49 (25%) for all profoundly retarded ICF/MR subjects.

Relationships Between Social Age and Demographic Variables

H₃: Amount of time subjects were institutionalized before ICF/MR placement will be negatively related to VSMS scores.

H₄: Age at time of institutionalization will be positively related to VSMS scores for ICF/MR subjects.

H₅: Number of years spent in ICF/MR will be positively related to VSMS scores.

Level of retardation was found to be related to SA, $r = -.62$, accounting for approximately 36% of the variance (see Appendix H). The negative nature of the correlation is due to the level of retardation classification system, i.e., moderate retardation = level 3, severe retardation = level 4, and profound retardation = level 5. The results verify that less retarded persons exhibit a higher level of adaptive skills than do those who function at a lower intellectual level. No other correlations were significant (see Appendix I) and the hypotheses for effects related to length of time institutionalized before ICF/MR placement, age at institutionalization, and time spent in ICF/MR were not supported.

Summary

Results of the analyses supported hypotheses for differences due to ICF/MR placement and handicap conditions. The ICF/MR subjects consistently made progress while non-ICF/MR subjects failed to do so, and subjects with fewer major physical handicaps responded better than those with more handicaps. Relationships between Social Age and the demographic variables were not supported.

Chapter V will discuss the above results and their implications for the ICF/MR program and for education.

CHAPTER V DISCUSSION

The results of the present longitudinal study demonstrate that the residents of the Intermediate Care Facility for the Mentally Retarded (ICF/MR) training program at Sunland Center Gainesville have made significant adaptive growth.

Effects of ICF/MR Placement

Subjects at all three levels of retardation studied, moderate, severe, and profound, made significant progress while in the ICF/MR program. Although moderately retarded subjects experienced no change in Social Age (SA) after their first year in the program, progress thereafter was dramatic, with an SA gain of 1.82 over the next two years as compared to a gain of only .17 during the same time period for the control subjects. The lack of progress noted for the initial period following ICF/MR placement may be due to the fact that most of the higher level clients at Sunland have been placed in the community and many of those still in the institution remain there because of problematic behaviors that make them poor candidates for successful community living. The year following ICF/MR placement seems to have been necessary to bring some of the maladaptive behaviors under enough control to permit existing skills to manifest themselves and new skills

to be learned. This pattern was evident for three of the four moderately retarded clients studied individually, EF, KL, and MN (see Appendix B, Case Studies 3, 6, and 7). Severely retarded ICF/MR subjects made significant progress every year after ICF/MR placement but none before, attesting to the effectiveness of the training program.

Individual differences in ability and intelligence exist within levels of retardation. A blind, deaf, and medically involved person who is profoundly retarded is distinctly different than a profoundly retarded person who has some speech, can feed and dress himself or herself, and participates in social activities. Profoundly retarded ICF/MR subjects were therefore grouped by number of major physical handicaps and distinctly different results were found at each level of handicap. Profoundly retarded subjects who exhibit no major physical handicaps consistently function at a higher level than those with one major handicap, who in turn function more fully than those with two or more major handicaps, the only group not to make significant progress.

Three factors must be taken into consideration in interpreting the lack of progress for ICF/MR subjects with two or more major physical handicaps. First, no comparable control subjects were available for this group since all clients with major handicaps live in ICF/MR. It is not possible to say, therefore, how this group would have scored had they not been receiving the structure and training provided through the program. Secondly, is their non-significant gain of .24 over five years (as opposed to .55 and .50 for profoundly retarded with one and no handicaps, respectively) an indication that they have not profited from the program, or is it instead important that they have not regressed? In a population so severely handicapped, relative

stability may be the most realistic and desirable expectation. It must be remembered, too, that group statistics combine data and that not every handicapped individual failed to make significant progress. Thirdly, the VSMS is not sensitive to small changes in skill level since it only credits complete behaviors rather than individual components. A multiply handicapped client may have learned some of the different steps in a skill but not enough to warrant an increase in Social Age.

With some exceptions, results for control subjects were not significant. Adaptive growth for moderately retarded control subjects remained stable across the entire period studied. Both severely and profoundly retarded control subjects made progress during the period between entry to Sunland and ICF/MR placement (1979 SA score for control subjects) but none afterward, raising the question of whether they had reached their maximum growth or whether continued traditional placement in fact inhibited growth. Only the profoundly retarded control subjects made significant progress during the 1982-1983 year after the Center reorganization. Although their gain was statistically significant, the large number of subjects ($n = 179$), the previous downward trend (see Figure 4-3) and the gain of only .15 during this year caution against attaching too much importance to this finding.

In theory, the reorganization that occurred at unitization should have provided equal services to both ICF/MR and non-ICF/MR units. In actuality, it appears that care remained unequal. At the time of unitization in November, 1982, staffing in both ICF/MR and unlicensed units was equalized except that no housekeepers were assigned to

non-ICF/MR. All cottages were then expected to provide identical services for their residents. The lack of housekeepers has made self-care and daily living skills training more difficult in non-ICF/MR because the direct care staff assigned to these areas are responsible for custodial duties as well as training. Additionally, unlicensed facilities frequently have more staff vacancies and provide less regular training services for their residents because of ICF/MR licensure priorities. Even though increasing the number of staff does not necessarily insure improved client services (Blindert, 1975; Grant & Moores, 1977; Harris et al., 1974), there is a minimum staff requirement below which the provision of training services is extremely difficult.

Physical plant differences continue to exist between the two halves of the Center as well. The ICF/MR cottages were all renovated to meet licensure standards and are attractive living units with a census cap and a degree of privacy for their residents. Non-ICF/MR cottages retain the traditional large, open dormitory wing and day room. They have no census restrictions and are frequently crowded. Since non-ICF/MR facilities have more clients but the same number of staff positions as ICF/MR facilities, they have a higher staff-client ratio. Noisy, crowded conditions, a higher staff-client ratio, and fewer structured training and leisure activities undoubtedly contributed to the control subjects' lack of progress.

Despite restricted resources, there is an admirable staff attitude on many unlicensed cottages. The pressure to meet ICF/MR standards under less than ideal conditions has served as a motivator to many

staff who feel that the extra effort required to provide services results in better overall quality of life for the residents. On the other hand, many employees who do not believe in training for mentally retarded persons have gravitated to non-ICF/MR facilities.

Initial Differences Between Groups

Initial VSMS scores at Sunland were higher for severely and profoundly retarded control subjects than for comparable ICF/MR subjects. There does not appear to have been any one formal and purposeful decision to place lower-functioning clients into ICF/MR but non-random placement did apparently occur due to logistical and other reasons. The first facility to be licensed at Sunland was composed of profoundly retarded residents who were felt to be the most neglected (J. Bartley, personal communication, February 26, 1985), which skewed the data toward the severe-profound level of functioning. Clients who are functioning at a perceived adequate level are not usually referred to ICF/MR. Those who are referred generally score at a lower level because of handicaps or problematic behaviors which interfere with functioning level. The fact that severely and profoundly retarded ICF/MR clients initially had lower scores and made significant gains over time, often surpassing the level of the control subjects, supports the strength of the program and its applicability to all types of clients rather than only to well-behaved individuals who exhibit a willingness to learn.

Very high level clients were not placed in ICF/MR because their adaptive skills were already considered to be at a functional level

and their days were structured with vocational training assignments. Scores for these clients did not influence the sample since the mildly retarded were excluded from the study design.

Relationships Between Social Age and Demographic Variables

Relationships between Social Age and demographic variables were not found to be meaningful. Lemanowicz et al. (1980) found that growth lessened as the number of years institutionalized increased but the present study found no relationship between SA and number of years spent at Sunland before placement into the ICF/MR program. Residents who have lived in the institution for many years are as likely to benefit from ICF/MR placement as those persons living at Sunland only a few years. Lemanowicz et al.'s finding that socially deprived persons' growth increases after institutionalization would suggest that clients who spent more time in traditional care units at Sunland before being moved to the ICF/MR program would show more progress than clients who had not been as "socially deprived" prior to entering the program. Balla et al. (1974), on the other hand, found that children less deprived before institutionalization showed more development after 2.5 years than did the more deprived children. Results of the data and the case studies showed no relationship between the two variables and support neither of the two studies mentioned. Eyman et al. (1975) found that older, mildly retarded individuals made more adaptive gains than did younger or more severely retarded residents living in community homes. Chronological age of Sunland clients was

not found to be related to adaptive gain. More interestingly, age at placement into ICF/MR was not significantly correlated with SA.

Implications for ICF/MR

The funding and licensing of an ICF/MR unit does not in itself guarantee adequate service delivery to retarded residents (Bible & Sneed, 1976; Conroy & Bradley, 1981; Repp & Conroy, 1980). This study demonstrated that the ICF/MR program at Sunland Center is effective and that ICF/MR residents consistently made progress and give every indication of continuing to do so. Studies which have found ICF/MR to be ineffective have concentrated on the lack of resident training provided during non-survey periods (Bible & Sneed, 1976; Repp & Barton, 1980). Although state and federal surveys are unannounced as suggested by Bible and Sneed, this fact alone is probably not enough to sustain the intense level of activity necessary during the months between visits. The in-house monitoring system at Sunland was established to insure that services are provided as scheduled. Surveys by the in-house Quality Assurance Team and monthly self-monitoring by facilities appear to be responsible for much of the success of the program at Sunland. The ICF/MR standards and accountability are taken very seriously and every effort is made to operate at a consistently high level of performance. There is a point, however, at which reliability checks become so cumbersome that they may interfere with the actual delivery of services they are supposed to insure, and care is needed to avoid reaching this point. Overburdened and underappreciated staff will "burn out" and both the program and clients will suffer.

Staff performance is of primary importance in insuring client progress and compliance to licensure standards. Merely increasing the number of staff assigned to a unit does not guarantee appropriate services for the residents (Blindert, 1975; Grant & Moores, 1977; Harris et al., 1974; McCormick et al., 1975), nor is the amount of actual training provided to staff sufficient in itself (Gardner & Giampa, 1971). The value placed on staff efforts (McCormick et al., 1975) and the assignment of specific clients to staff so that all residents receive individualized attention (Grant & Moores, 1977) are also important. Studies of CD, IJ, KL, and KF (see Case Studies 2, 5, 6, and 8) illustrate the strong effects of individualized attention. Priority must be placed on hiring well-motivated, intelligent staff and then giving them the support and appreciation necessary for job fulfillment.

The findings of this study do not support any selective policy for resident selection. The range of intellectual, adaptive, and physical functioning levels is so diverse in the developmentally delayed population that it would be extremely difficult to arrive at a consensus of exactly who will or will not benefit from training. In addition to basic variables such as intelligence and number of handicaps, intangible factors such as willingness to learn and responsiveness to structure and contingencies are important in determining a person's appropriateness for placement in an intensive training program. This type of information should be obtained from the resident's Interdisciplinary Team, which is most familiar with each client's response to a high-stimulation/demand environment.

It does appear, though, that the most unresponsive to training are those residents like CJ (see Case Study 9) whose mental retardation is complicated by psychosis. Persons in this category are frequently unresponsive to their environment and respond inconsistently, if at all, to reinforcers and contingencies. Additionally, the intense and unpredictable nature of their behavior often poses a substantial threat to the safety of both peers and staff. An intensive training facility with tight control over the environment can be effective for some persons whose thought processes are loosely grounded in reality, as with AB, CD, MN, and RW (see Case Studies 1, 2, 7, and 10) but it can also exacerbate the situation.

Intellectual or adaptive growth, while important, cannot be the only criteria for success. Intangible factors also influence client progress. Social progress will often signal concurrent growth in formal programming areas and maladaptive behaviors often improve without formal programming under such conditions, as was the case with CD, IJ, and KL (see Appendix B, Case Studies 2, 5, and 6). Conversely, improvement of problematic behaviors often permits training progress, as happened with EF and GH (see Case Studies 3 and 4). Given the complex nature of behavior, a holistic approach is necessary to address each individual's strengths and weaknesses.

The lack of progress of the multiply handicapped profoundly retarded subjects speaks to the question of "heroic efforts" and the cost benefit of attempting to train multiply handicapped and unresponsive persons in traditional areas such as self-care, motor and basic academic skills (Bailey, 1981). Efforts (and funds) may be

better directed toward "stimulation programming" to prevent regression rather than toward "teaching programming." Such an approach would also free some trainers to concentrate on higher-level clients who have been shown to benefit from such attention and who are not now receiving the additional training.

Implications for Education

This study demonstrated that moderately, severely, and profoundly retarded persons respond to an intensive training regimen which employs basic principles of learning theory. Residents not participating in the program maintained their level of adaptive functioning in the absence of special training but showed little overall progress. The success of non-punishment contingency management in decreasing inappropriate behaviors suggests that, with students of normal intelligence who possess verbal and conceptual skills far advanced over those in this study, similar behavioral intervention will be effective in lieu of corporal punishment.

The ICF/MR program operates under strict guidelines which insure delivery of similar services to all residents. This uniformity serves a quality control function but can become stifling. As demonstrated by the case studies, most students benefit from a somewhat individualized instruction approach.

The actual number of available instructors/staff does not necessarily affect learning unless the staff are properly trained and motivated. Mandating a particular educational approach or adding more teachers or aides to the classroom may be ineffective unless

measures exist to insure that instruction is being delivered correctly. In conjunction with accountability and monitoring, care must be taken to respect instructors' skills and allow them freedom to work.

Limitations of the Present Study

Control subjects were unavailable for the multiply handicapped profoundly retarded condition since all residents who met these criteria resided in ICF/MR units. The significance of their limited progresses was thus difficult to assess but nonetheless suggests that they have benefitted from the program. Control subjects were available for all other groups.

The Vineland Scale of Social Maturity (VSMS) has been criticized because of its nature as a third-party interview instrument. Although the VSMS can be criticized for reliability, so can any other standardized measure of adaptive or intellectual level which is used with a developmentally delayed population. Effects of examiner familiarity, client health, responsiveness, and problematic behaviors all influence test results. The VSMS was felt to be an appropriate instrument for this study because of its administration at Sunland by select and trained examiners, the specific interpretive criteria which have been developed for Sunland, and the relative consistency of client scores from year to year. Although the use of the VSMS has been criticized, it has also been supported and the interview nature of the instrument is not seen as more than a very minor limitation.

Suggestions for Additional Research

A review of the literature discloses a paucity of research on the effectiveness of the Intermediate Care Facility for the Mentally Retarded program. Reported studies suggest that this expensive national program has great potential but lacks consistent implementation. Pro- and anti-deinstitutionalization proponents continue to search for the one optimum placement for developmentally delayed individuals. This author's opinion is that a combination of services and placement, both institutional and community, will probably always be required due to the extremely diverse population under consideration. The ICF/MR program can play an important role in correctly placing these persons.

Even assuming that community placements were without fault, a patently false hypothesis, 1,015 mentally retarded clients in Florida alone were waiting for residential placement as of December, 1984, and many will remain on the waiting list for three or four years before an opening becomes available ("More Help Needed," 1984, p. 14-A). Additionally, the Reagan administration has questioned the Pennhurst decision and argued that "the mentally retarded have no federal right to training that would develop their capacities to the fullest extent possible and no right to community living arrangements" and that they are entitled only to "freedom from unreasonable bodily restraints and to such training as is required to reduce the need for bodily restraints and promote physical safety" ("Administration Argues," 1984, p. 5-A).

Empirical evidence is necessary to support policy decisions by those in positions of authority but current research is often

contradictory. Longitudinal data and objective measures of growth can provide the necessary information. Several useful instruments exist to measure environmental and individual characteristics objectively including the Program Analysis of Service Systems (PASS), the AAMD Adaptive Behavior Scale (ABS), and the 1984 revision of the VSMS. Conroy (1979) has outlined theoretical dimensions of quality and operational measures of quantity which may serve as useful research guidelines. Criteria such as "wariness" are interesting but vague, do not allow comparisons between studies and institutions, and do not provide positive guidelines for future placement of and delivery of services to residents. Personality and mental health characteristics are important in predicting an individual client's response to training strategies but must be objectively defined and replicable when used as data bases for research.

The poor response of some mentally retarded psychotic residents to ICF/MR placement indicates a need for research in this area. Effective placement for persons suffering from both mental retardation and mental illness remains to be established. Is their behavior more functional in an environment geared toward treating the mentally retarded or the mentally ill? Effective strategies for working with dually diagnosed persons who are essentially unresponsive to contingencies are badly needed.

Social Age gain for non-ICF/MR Sunland clients during the year following unitization was not significant. Further follow-up is needed to determine whether the lack of growth under presumed improved living and training conditions was temporary and possibly due to

initial adjustment factors, either client or staff, or if the intervention will indeed be effective. If non-ICF/MR subjects' growth begins to equal that of their ICF/MR counterparts, the argument may be presented that the expense of ICF/MR is not necessary in order to provide a healthy environment. It must be remembered, however, that non-ICF/MR units at Sunland operate under close to ICF/MR standards and as such are more expensive than traditional custodial units.

Conclusion

Moderately, severely, and profoundly retarded individuals respond well to intensive training and structure, progressing both in adaptive skills and appropriate behaviors. The Intermediate Care Facility for the Mentally Retarded program at Sunland Center, Gainesville, provides an environment that is capable of producing such growth. Neither traditional care practices nor improved care after unitization produced significant progress.

The ICF/MR program is intensive and expensive but is designed to be an intermediate program step between institutional and community placement rather than a permanent living arrangement. Instead of continuing the institutionalization-deinstitutionalization battle, emphasis should be placed on locating the most appropriate placement for each individual resident. Attention must be paid to diminishing transition shock and improving client adjustment to the community (and community adjustment to the client) so that community placements will be successful and return to the institution unnecessary. In conjunction

with improved adjustment skills, an adequate number and quality of community residences must be established so that ICF/MR clients who have developed appropriate skills can be moved out of the institution. Such development of resources will utilize the ICF/MR program according to its goals, will depopulate the institution and reduce crowded conditions on remaining cottages, and should lower the cost of running the institution as the census is lowered and fewer support services are required. In this way, those residents who have adequate functional skills and behavior for community living will profit from a non-institutional environment while those residents who continue to require more intensive treatment for whatever reason, medical, functional, or behavioral, will remain in the institution.

"Many of the problems that we're called in to treat are the result of living in pathogenic environments" (Risley, 1982, p. 3). Factors relevant to client development in an institution include the amount of day programming, degree of individualized treatment, and number of (psychotropic) medications prescribed (Conroy & Bradley, 1981). Given the results of the present study, it may be said that the ICF/MR program at Sunland has greatly modified the traditional institutional setting to provide a healthy environment and one which meets Conroy and Bradley's criteria. The "snake pit" has been tamed.

APPENDIX A
CLARIFICATIONS ON VINELAND SOCIAL MATURITY
SCALE SCORINGS

Item Number	Clarification
4 Soc	What behaviors are included in "reaches for familiar persons"? If the client differentiates family from strangers and/or reacts differently to different staff members, score +; if not, score -. "Reacting" means initiating a response.
7 Occ	Does "occupies self unattended" include self-stimulation? If the self-stimulation is not harmful, score +; if it requires intervention, score $\pm$.
10 Comm	Which sounds are included in "imitates sounds"? Are self-stimulatory sounds, noises, and crying included? Only sounds with speech-like inflections should be scored +.
14 Soc	What behaviors indicate "demands personal attention"? A primary criterion is that the client must initiate the behavior. In the case of a severely handicapped client, following staff member with eyes might be sufficient.
18 Loc	How is "walks about room unattended" scored for non-ambulatory clients? It should be scored + for a client who is wheelchair mobile; any level of mobility below this is scored -.
22 Occ	How liberally is "transfers objects" interpreted? This cannot be hand-to-hand transfer of objects in a manipulative manner only; the behavior must indicate purposeful placement of an object. The placement of a piece in the form board is scored +.

- 26
SHG "Gives up baby carriage." How do we score this for a wheel chair client?
- If the client is wheel chair mobile, score +; if he is partially mobile, score ±.
- 30
SHE Is food on the floor an "edible substance"?
- Score + if client does not eat trash, whether or not he eats food off floor.
- 33
SHE How do we score "unwraps candy" if client is never given wrapped candy?
- If there is really no opportunity, score NO. If client peels a banana or opens a bag of chips, score +.
- 34
Comm "Talks in short sentences."
- Speech must be meaningful and must combine at least two words to be scored +; size of vocabulary is of less importance.
If speech occurs only occasionally and/or only in response to specific persons, score ±.
- 35
SHG "Asks to go to toilet."
- This should be scored strictly according to the VSMS manual.
- 36
Occ Does "initiates own play activities" include watching and reacting to TV?
- Does it include playing with string or non-toys?
Does it include self-stimulation?
- Score + for both active watching of TV and playing with non-toys.
Score - for self-stimulation.
- 38
SHE "Eats with fork."
- This item will have to be scored NO for clients on many cottages.
- 39
SHE Does "gets drink unassisted" include use of water fountain? Would it include drinking from the commode?
- Score unassisted use of water fountain +; score drinking from commode -.

- 41
SHG Many of these "simple hazards" do not occur in the Sunland environment. Would "hazards" include an angry client?
- Group Reached no firm conclusions, but felt (1) this did not include avoiding another client and (2) staying out of the street is important, but not definitive.
- 43
Occ How liberally do we score "cuts with scissors"?
- If possible, we should give the client a trial with scissors and/or get a fairly detailed report. On this item use NO liberally.
- 45
Loc Should client receive credit for "walks downstairs one step per tread" without assistance if he uses the stair railing?
- In scoring this item, do not count use of railing as assistance.
If client is handicapped and can get downstairs alone in any manner, allow $\frac{1}{2}$ credit.
- 46
Soc Must the client know and observe the rules of the game in order to receive credit for "plays cooperatively at kindergarten level"?
- This item does not include knowing and/or observing rules. The item is scored + if the game is supervised by an adult. The item is scored + if the client plays with one other person in an organized manner.
- 49
Soc "Performs for others."
- To be scored +, the performance must be either carried out by request and/or be clearly intended for the entertainment of others.
- 50
SHD "Washes hands unaided."
- This item may be scored + if the client requires verbal reminders and/or cues, but should be scored - if he requires physical assistance.
The item does not require that the client adjust the water temperature.
- 51
SHG "Cares for self at toilet."
- If the client cares for himself completely in toileting except for the use of tissue and tissue is not available, score this item +.

52 "Washes face unassisted."

As in item 50, the item should be scored + if the client requires verbal reminders and/or cues, but should be scored - if physical assistance is required.

53 "Goes about neighborhood unattended."
Loc

If the client goes to any off-cottage activity unattended, this item is scored +; if he must be observed all the way, score ±.

54 "Dresses self except tying."
SHD

Client should receive no credit for this item if he dresses with slip-on type clothing only; to receive credit, his dressing skills must include fasteners.

NOTE: If item 47 is -, this item must be -.

56 "Plays competitive exercise games."
Soc

Examples of activities at Sunland which should be scored + are Special Olympics, kick ball games, and throwing a basketball with other clients.

57 "Uses skates, sled, wagon."
Occ

If item 53 is scored + and the client rides a bicycle or tricycle around campus, score this item +.

59 "Plays simple table games."
Soc

Activities scored + will include card games, table games, and pool games.

60 "Is trusted with money."
Self-
Dir

Score this item + if the client can be trusted to take his own money or someone else's money and buy items at the canteen.

61 "Goes to school unattended."
Loc

This item should be scored + if item 63 is + and the client goes from one place on campus to another place on campus three or more blocks distant unattended and unwatched.

All clients acting as messengers around campus should receive + score.

- 62
SHE "Uses table knife for spreading."
If client does not have access to a knife and uses a spoon for this purpose, score +.
- 64
SHD "Bathes self assisted."
"Assistance" may be verbal cues, setting water temperature, shampooing.
To score + client must soap and rinse all body parts with no physical assistance.
- 65
SHD "Goes to bed unassisted."
In the Sunland environment, this is scored + if client gets into his own night clothes without assistance and goes to his own bed.
- 67
SHE "Uses table knife for cutting."
This is to be scored + only if item 62 is +.
- 68
Soc "Disavows literal Santa Claus."
If possible, ask the client if Santa Claus is a real person and score accordingly.
- 69
Soc "Participates in pre-adolescent play."
To score + on this item, the activity (1) must be client initiated and/or be carried on without adult leadership, (2) must involve purposeful activity, and (3) must involve physical activity.
- 71
Occ "Uses tools or utensils."
Occ The "tools" may include broom and mop.
The item is scored + only if the client habitually uses more than one tool.
Client should not receive credit for Sheltered Workshop activities if he does not use tools in other settings.
- 72
Occ "Does routine household tasks."
This item is scored + even if the client requires some verbal prompts.
If client performs one cottage chore only, allow $\frac{1}{2}$ credit.

APPENDIX B
CASE STUDIES

CASE STUDY #1

Demography

AB is a twenty-five year old black male who has been diagnosed autistic. His mental retardation is related to premature delivery and his IQ, as obtained on the Stanford-Binet Form LM, is 13 (Profound level of functioning). He has no physical handicaps other than early cataracts, which do not seem to interfere with his daily functioning. He has lived at Sunland since the age of eight and was moved to his present ICF/MR cottage at the age of twenty-one.

AB engages in high levels of self-stimulatory physical activity and requires a high calorie diet just to maintain his weight. He is a somewhat picky eater and eats in "patterns," e.g., will eat around and around the edge of his mashed potatoes until they are consumed. He ruminates after meals (regurgitates and re-eats his food) but the duration of each incident is short and thus no dental, medical, or dietary problems have resulted.

AB is very muscular and fit, undoubtedly due to frequent and vigorous self-stimulatory rocking and bouncing. He is extremely well coordinated and, when upset, will sometimes run "full speed" at a wall, turn 180° at the last moment and then hit the wall very solidly with his back. Other autistic behaviors he exhibits include twirling a stick in front of his eyes, smelling objects, and stretching the bottom

front of his t-shirt so that it will billow in the air as he moves it up and down. AB has a short attention span when engaged in anything except self-stimulatory behavior, and does not initiate contact with others.

Behavior

AB engages in self-stimulation during most of his unscheduled time but has also exhibited some more serious behaviors. He previously urinated and masturbated outdoors but now performs these activities in more appropriate locations. In February 1983 he began to masturbate excessively (from 1 1/2 to 5 hours per night). This behavior continued during the day as well and posed a threat to his well being since he was sleeping very little. He was referred to psychiatric clinic and Tofranil was prescribed. The intervention was successful and there have been no further reports of the behavior occurring excessively.

AB once had frequent, sometimes daily, tantrums but his behavior has shown great improvement since he and his cottage mates have been able to eat in their own dining room rather than in the central dining hall. The central dining hall is noisy and chaotic and AB often became very agitated, jumped up and down, and bit himself. These behaviors stopped once he was able to eat in a calmer atmosphere and no longer had to wait in line to obtain his food. Presently he becomes upset only about twice per month; some tantrums are attributable to displeasure with events and others occur for no apparent reason.

Mellaril was prescribed in 1969 to help control AB's behavior but was discontinued in 1982 when he was diagnosed autistic. The

consulting psychiatrist prescribed Haldol (1 mg twice daily) based on work which claimed some success treating autistic symptoms using small doses of Haldol. AB appears to have responded to this regimen and has become slightly more responsive to staff, sometimes going into the cottage manager's office to look at magazines. Personal contact remains infrequent, however, and most interactions or training responses center around food. He does respond better to staff interruption of his self-stimulation and will now frequently sit in a chair rather than throwing a tantrum when told to get up from the floor.

Programming

AB has shown fair response to training since his placement in ICF/MR. He has learned to brush his teeth and his oral hygiene has shown improvement. Academic goals of pointing to objects and maintaining eye contact have been unsuccessful, and so he is now working on staying on task for ten minutes. A goal to sign words has met with mixed success. The most successful signs for AB have been "eat" and "drink," which he emits only to obtain edible reinforcers. He has consistently met the goal to attend leisure time activities, has made progress in using cutting, pasting and coloring skills in arts and crafts projects, and has met the goal to play group ball games. AB has learned to use appropriate utensils at mealtime, make his bed, blow his nose using tissue, mop and sweep, and use the washing machine. He is also learning to take action for self survival by independently exiting the building during a fire drill when one or more of the exits are blocked.

Summary

AB has made good progress since his placement in ICF/MR. His Social Age dropped from 4.0 in 1980 to 3.3 one year after ICF/MR placement (see Figure 1) but increased to 5.3 three years later. Programmatic goals have been refined and tailored to his needs and he continues to show improvement in spite of autistic symptoms. Although he remains very withdrawn and primarily engages in self-stimulatory behavior, AB has become more sociable and his tantrums have decreased to the point where they are no longer considered a problem. He lives in a very active cottage and recently became upset when some other clients were taken to a movie and he was left behind, a positive sign since he is generally withdrawn and apparently indifferent to his surroundings.

While the evidence is not conclusive, it does appear that the 1982 medication change from Mellaril to Haldol was of help in improving AB's interpersonal skills and response to training. His VSMS scores continue to show a steady increase and the interdisciplinary team has recommended that he remain in his current Sunland ICF/MR cottage since he continues to benefit from the placement.

CASE STUDY #2

Demography

CD is a thirty-one year old profoundly retarded white male who has lived at Sunland since the age of seven and was transferred to ICF/MR in 1980 at the age of twenty-seven. His mental retardation is associated with autism (childhood schizophrenia), a "mental illness . . . characterized by severe withdrawal and inappropriate response to external stimulation . . . and (often) serious impair(ment) in general intellectual functioning" (Grossman, 1977, p. 124). According to reports from CD's family, he developed normally until around age 4, had a large vocabulary, sang numerous nursery rhymes, and attended regular nursery school until his behavior became unacceptable and finally necessitated institutionalization. His family has recounted several possibly traumatic events that occurred during that time of his life, including a fall on his head and witnessing several puppies being unintentionally run over by his father and skinned alive. It is not known what, if any, effect these events had on CD.

CD no longer spoke after his placement at Sunland. His family feels that he was angry at them for leaving him; it is more probable that the lack of stimulation at Sunland at that time simply allowed him to regress. His family is supportive and visits him regularly.

His response to them varies; sometimes he knows them and at other times he does not seem to.

Behavior

CD's behavior deteriorated after his placement at Sunland to the point where he exhibited severe self-abusiveness and aggressiveness. He has two very large "cauliflower" ears, permanently misshapen from years of hitting himself. Remarkably, his hearing remains functionally intact even though neither ear has enough of an opening to permit examination or irrigation. Physical restraints were frequently required in earlier years to prevent CD from injuring himself or others, and he was able even then to bite others.

Restraints were no longer required by the time CD entered the ICF/MR program but aggression and self-injurious behavior (SIB) remained frequent. Additionally, he frequently wet his bed and urinated in public areas. He chewed tobacco or dirty cigarette butts, drooled tobacco juice and spit it on the floor and furniture. Public masturbation was frequent. Not surprisingly, staff said they were ready to pack his bags at a moment's notice.

A DRO behavior program was developed which used tobacco, food, and praise as reinforcers. In addition to behavioral intervention, CD continued to receive Mellaril and Lithium daily. In 1982, after two years in an ICF/MR cottage, incidents of self-abuse (face slapping and head banging) had decreased from an average of 20 per day to only 2 per day. Aggression occurred only once every three days, and was no longer severe when it did occur.

CD had some dental work done and suffered a severe psychotic reaction when the dentist gave him Catamine, a tranquilizer. He became extremely self-abusive and aggressive, and masturbated almost constantly, apparently with great discomfort. It became necessary to dramatically increase the Mellaril until his behavior could be brought under control once again. Control was reestablished and by 1983 SIB had decreased to 3 episodes per week and aggression to one incident per month. Tearing clothing and inappropriate undressing decreased to zero, and he learned to masturbate in private. He continued to chew on cigarette butts but spit them out when requested to do so, especially at meal times. In 1984 CD's formal behavior program was discontinued due to the great improvement in his behavior, which then averaged eight minor incidents of self-abuse per month and only one incident of aggression in five months.

CD remained basically nonverbal but once surprised a staff member by clearly asking him something to the effect of "how're you doing today" and then became silent again. Since his records indicate that he had once spoken fluently, staff began to require him to ask for things he wanted, which he did very reluctantly and in a muffled voice. Attempts to take food from others at meals ceased after he was made to leave the eating area and not return until he had apologized to the victim. CD did this, crying tears, and did not snatch food again. Object permanence appeared to develop as he watched staff members' coffee during meetings even after they hid it from his view, whereas previously he would walk away as though it no longer existed. He also began to emit some spontaneous and clear phrases, often completely out of context, such as "want some ice cream" and "Africa."

For most of his institutionalized life, CD has been a real "loner" and concerned only with ensuring his own comfort. In 1982 he began to respond to a staff member who played with him by chasing him around the cottage. This was considered to be a positive behavior but increased to the point where he began to run away from the cottage, searching for discarded cigarette butts and apparently quite pleased with his new found ability to control staff behavior by making them chase him. He has progressed and presently is allowed to go outside by himself, although staff must still watch him closely and escort him to any destinations.

Since his ICF/MR placement in 1980, CD has progressed from an antisocial, self-abusive, and aggressive individual to a happy and often sociable young man. He retains the autistic symptoms which impair his functioning, but he has made remarkable progress. To give one example, his parents were able to take him out in the car with them on their last visit, a previously impossible feat due to his extreme behavior problems and lack of compliance.

Programming

CD has made such good progress behaviorally and in his training programs that he is now able to attend some off-cottage activities. He continues to be somewhat stubborn and noncompliant but much less than previously and is clearly benefitting from his training. As a result of staff efforts to make him name objects before receiving them, his language receptiveness has progressed to the point where he is now

in formal speech therapy. He has been enrolled in the facility prevocational program and is doing well, although he still requires a cottage escort to stay on task. His behavior there is appropriate, a great improvement from that of last year when he often urinated on the floor and masturbated during sessions. Sessions address packaging, assembling, and sorting skills but the formal goals are for on-task behavior and, hopefully within the year, behavioral improvement so that he will be able to remain at work without requiring a cottage escort. In his cottage training, CD is learning to bathe himself independently, care for his fingernails, make his bed, and identify himself in a photo. He participates in regularly scheduled arts and crafts sessions and activities.

Comments

CD is a client whose retardation is due to psychosis. He has made good progress through a combination of formal programming and staff attention and continues to develop. Many of CD's former skills appear to remain intact but inaccessible, as evidenced by his occasional lucid speech and his response to some complex commands. Mellaril and Lithium continue to be necessary for his daily functioning but it is hoped that they may be lowered or discontinued in the future.

A review of CD's VSMS scores at Sunland (see Figure 2) shows an unexplained jump in 1976 from 2.1 to 5.4 years and then a steady decline until 1981 when the scores began to rise again. Scores fell an average of .6 from 1976 until his move to ICF/MF in 1980. His social age after

one year in ICF/MR fell again but only dropped .1 and then began the rapid increase which as yet shows no indication of leveling off.

CD is responding well to training and it is not now known how far he can, or will, advance. Previous attempts to transfer him to Marianna Sunland to be nearer to his family have been abandoned since it is felt that any change in his environment at present would be extremely detrimental to his development. Programming is very important, but just as important to his present growth are the cottage environment and the staff's responses to him. CD has gone from being an unhappy, self-abusive and aggressive individual to being the cottage "pet."

CASE STUDY #3

Demographics

EF is a twenty-seven year old moderately retarded white female whose retardation is due to birth injury. She has lived at Sunland since she was twelve and moved into ICF/MR at the age of twenty-three. She has no physical handicaps except epilepsy and scoliosis (curvature of the spine), which has been stable since surgery in 1971. EF must wear a helmet to avoid injury due to the force of her falls when having seizures. Her attractiveness is considerably lessened by the helmet but it is necessary since she has broken her jaw twice and has required numerous head stitches due to falls.

Behavior

The authenticity of EF's seizures is often uncertain. Undoubtedly some have been "real," but she is a master at "faking" seizures. Numerous medical tests and two hospital stays have been unsuccessful in determining conclusively the etiology of her seizures.

Staff feel that some of the seizures are authentic but that the majority are probably false. During an apparent grand mal seizure they have told her that her sister has come to visit and EF has jumped up, fully coherent, to look for the sister. This kind of response

should be impossible during authentic grand mal activity. Additionally, EF has admitted to staff that she has indeed faked some seizures. Her motivation often seems to have been to escape from unpleasant situations at her cottage or work site.

The more puzzling seizures have occurred prior to home visits or when EF has attempted to persuade her doctor that she no longer needs a helmet. She is told that the helmet will be removed once he is sure that there is no longer any danger to her from seizures. For some reason she then tries to prove how well she's doing by having seizures, sometimes nine or ten every day for two to three weeks. Even though EF is quite verbal and can explain how to satisfy the doctor, her actions do not match her words. She may be thinking that the seizures draw attention to her plight and seems to feel that being seizure-free for a few hours is proof enough of her good health.

EF has a long history of seizure activity before holidays which may be the result of superstitious attempts to insure that family members come to take her home. She may have had some real seizures in the past immediately preceding a home visit and has ascribed a causal relationship to the two events. She has also had repeated seizures during family visits at Sunland when her relatives attempted to leave and has successfully postponed their departure.

A jaw broken during seizure activity resulted in a very pleasant stay in the hospital for EF. Medication prevented any pain, she had full run of the building, staff to visit, and a private room. Additionally, her sister came to visit and brought gifts and food.

The sister was contacted at the time of EF's next seizure-related hospitalization and agreed to restrict her visits to healthy, seizure-free times. This was explained to EF and strictly enforced. Additionally, home visits were made contingent on a seizure-free condition. Frequency of seizures dropped from as high as twelve per day to zero the day the contingencies were instituted and remained at zero for several months. The rapidity with which EF responded to the contingencies, considered in conjunction with blood levels that showed all her anticonvulsants to be within therapeutic range, clearly suggests that she has a great deal of control over her seizure activity and strongly supports the fake seizure hypothesis.

EF remained seizure-free for five months in 1983, a record length of time for her, and the physician seriously considered removing her helmet. A new director of pharmacy started work at that time and EF responded badly to his interest in her seizure pattern. He was young and handsome, and before he ever got back to his office from visiting EF at her cottage she had begun another bout of seizures, apparently to encourage his attention. He made no further contacts with her and the medical staff put her on cottage hold, a previously effective contingency which EF referred to as her "punishment." This time, however, the consequences appeared to be ineffective and the seizure activity escalated. It appeared that cottage restriction had become reinforcing to her and so the procedure was changed. She was treated like any other seizure patient and staff recorded the seizures but otherwise ignored them unless she received an injury. Medical attention was given as neutrally as possible so as not to further reinforce the

seizures and shape in self-abuse by successively reinforcing more serious injuries. This approach seems to have been successful since the seizures are once again under control.

EF did janitorial work at the Sunland dining hall for several years but in 1984 began to have seizures there almost daily when asked to do something she did not want to do, or when her boyfriend was nearby. The environmental manipulation of moving her to the ceramics shop appears to have been successful and she has had no more seizures while at work.

EF has recently experienced a great deal of emotional stress. She had never had any seizures while at home until the seventeen that occurred during a home visit in 1984, probably a jealous response to her sister's new baby. Additionally, her steady boyfriend recently broke off their relationship and she has been quite depressed as a result. She has finally begun to talk about her sister's baby but still remains depressed over her boyfriend. The facility psychologist is meeting regularly with EF in an attempt to help her deal with her feelings which, although painful, are seen as a sign of emotional growth.

Inappropriate behaviors of stealing money, noncompliance, and stubbornness have all decreased in frequency. A "report card" system was instituted to record EF's daily behavior and reinforce good behavior at the end of each day with a soda. She enjoys the drink but seems to be more reinforced by showing a good report card to staff. She also carries the card to work so that all of her daily activities are recorded and consequated.

Programming

EF has all of her self-care skills, including operating the washer and dryer, and is working on goals such as describing traits that make people desirable to be around, dialing the telephone, and telling time. Training programs continue to refine her already good skills but the main emphasis has been on behavioral improvement. She functions at a very high level and prefers to think of herself as a "staff person" rather than as a resident. She can be very stubborn when asked to do something and often refuses or whines about the request. Additionally, she attempts to verbally manipulate staff. It has been necessary to remind them that, although EF appears to be quite competent, she is nonetheless retarded and not capable of the high level of abstract reasoning they sometimes expect of her.

Summary

A review of EF's Social Age scores at Sunland (see Figure 3) shows variable progress but a steady upward trend overall. Before her placement in ICF/MR her social age scores ranged from 7.7 to 8.1 years, a difference of .4. Since ICF/MR placement her scores have ranged from 8.6 to 9.2. She has gained .6 years and is showing a more rapid acceleration than previously.

EF has made such good overall progress that the IDT team has recommended she be moved to a community group living home near her family. Actual placement is unfortunately doubtful since community resources are limited, but it is significant that she has been

recommended. She requires a setting with firm structure and staff familiar with behavioral programming. Inconsistent or incorrect consequences for her behaviors could result in recovery of her inappropriate behaviors of stealing, noncompliance, and especially faking seizures. While such a placement is the most desirable, it is expected that EF will continue to benefit from the structure and training provided through her present Sunland ICF/MR cottage.

CASE STUDY #4

Demographics

GH is a twenty-five year old while female who was placed in Sunland when she was eight years old and moved to ICF/MR in 1980 at the age of twenty-two. She is moderately retarded due to phenylketonuria (PKU), an inherited disorder characterized by an inability to oxidize a metabolic product of phenylalanine and which results in mental retardation unless a special diet is prescribed at birth. (This diet had not yet been developed at the time of GH's birth.) She is epileptic but has been seizure-free since 1975. She receives Phenobarbital and Dilantin to control seizures and Sinequan, an antidepressant, to help control her behavior. The Mellaril and Haldol she received in previous years were discontinued as her behavior improved, and Phenobarbital is being tapered out because of the length of time since her last seizure.

GH can speak in articulate, complete sentences but often prefers to use phrases or single words. She will carry on lengthy monologues with herself about herself ("GH, you shouldn't do that. You know you're supposed to behave.") and refer to herself in the third person when speaking with others ("GH wants to go to the dance. She likes to do that."). Staff are now encouraging her to speak in the first person and her inappropriate speech has lessened somewhat but still occurs at a high frequency.

Behavior

GH has had a history of severe tantrums involving destruction and aggression. Although she is of slight build she is quite difficult to control when aggressive or destructive. Tantrums occur primarily because of her inability (refusal) to postpone gratification, usually food or an anticipated event. Inappropriate behaviors have been restricted to the cottage or home and have not occurred at school or at work, probably because she can talk other clients into buying her food or sodas at these places. (Interestingly, frequent access to beverages and food at the cottage results in a worsening of GH's behavior but causes no such problems at work.) Staff at school and work are not included in her behavior program except to provide positive feedback since her behavior is appropriate in their areas.

A "report card" was developed in 1982 which is filled out daily by staff and lets them know when GH has earned her reinforcers. Her response to this program has been very good. Tantrums decreased from five per week in 1982 to 2 per week in 1983 and are much less intense. She now frequently responds to staff verbal intervention, principally repeated explanations about why she must wait for something, rather than requiring a physical takedown during every tantrum. She has frequent, usually weekly, home visits and has shown the same progress there. Her family has worked with the cottage staff by not taking her home after a tantrum so that GH has learned that home visits are related to cottage behavior.

Programming

GH has most of her self-care and daily living skills and has learned to care for minor injuries. She is presently in training to identify female restroom signs, describe human emotions, and sequence the stages of human development. She has also completed programs to describe laws and the consequences of breaking them, as well as changes that occur at puberty. She has worked in the sheltered work shop learning packaging skills and now works at the recycling plant where she prepares newspapers for a baler.

Summary

GH has had a long and stormy history of severe tantrums which have disrupted cottage and family life. She has made excellent progress through a combination of cottage/home consistency, behavioral programming, psychotropic medication, and staff willingness to help her develop the ability to delay gratification. She has benefitted from the positive atmosphere of the cottage and now enjoys attending social activities.

GH's Social Age scores dropped steadily from 8.1 to 6.5 years in the period 1977-1980 (see Figure 4). The trend reversed itself dramatically after ICF/MR placement and her Social Age rose to 8.4 in 1982.

The IDT team agrees that GH's skills are at an appropriate level for community living but that she will require a placement with staff who are very consistent and have some background in behavioral

programming. If her behavior is consequted inconsistently her tantrums will most likely return to their previous intensity. Until an appropriate placement is found GH will continue to live in her present Sunland ICF/MR cottage and is expected to continue to benefit and develop self-control.

CASE STUDY #5

Demographics

IJ is a twenty-nine year old white male who is severely retarded due to unknown causes. He is epileptic but his seizures are under excellent control with a very small dose of Phenobarbital. His speech is intelligible and he has no physical handicaps. He has lived at Sunland since the age of ten, was placed in ICF/MR when he was twenty-two, and moved to his present ICF/MR cottage in 1982 at the age of twenty-seven.

IJ has an extremely supportive family and greatly enjoys any contact with them. Visits home were frequent until his behavior became very aggressive at the end of every visit. After several different and unsuccessful interventions, it was reluctantly decided that visits at the cottage were most appropriate and home visits were discontinued.

Behavior

IJ is very aware of his surroundings and has good verbal skills. He generally keeps to himself, often in his room or in a private area where he can play with a ball. He has little interaction with his peers and prefers to be around staff when he is feeling sociable. When he first moved to his present cottage he remained completely isolated but now will spend some time with staff in the office or

training room. IJ is resistive to structure but does require firm limits. Attempts to improve his behavior by making the cottage as pleasant and undemanding as possible for him backfired and his behavior worsened. A combination of a pleasant environment and definite, firm limits has been the most effective approach.

Inappropriate behaviors include screaming, running around the cottage, breaking windows (the glass has now been replaced with plexiglass), tearing clothing, and some aggression toward others. Episodes of inappropriate behavior averaged 10 per week in late 1982 and are presently averaging 2 per month. There is often no apparent precursor to tantrums but sometimes staff are able to calm him down before he becomes very upset.

The sudden and violent nature of IJ's outbursts suggested possible psychomotor (temporal lobe) seizures but an EEG gave no indication of this. Furthermore, the administration of an anticonvulsant had no apparent effect on his behavior.

A combination of Mellaril and behavioral programming was effective in maintaining some control over IJ's behavior until he displayed symptoms of tardive dyskinesia and the Mellaril had to be immediately discontinued. His behavior worsened considerably when he was taken off the Mellaril but he did respond to staff consistency and firmness. A behavior program was instituted to reinforce appropriate behavior but has had minimal success since no reinforcer has been found for IJ that is powerful enough to avert a tantrum.

IJ continues to behave inappropriately at times but has shown great improvement. He will now join staff and other clients for a

morning cup of coffee and discussion after breakfast. He continues to spend time by himself but has begun to play with his ball out in the front yard instead of in his bedroom or on the floor in the shower area. Previous resistance to attending cottage activities has lessened and he will now ride in a van to attend movies and dances on Center. He is very picky about food and knowing that certain disliked foods are on the daily menu has frequently precipitated tantrums. (He has memorized the entire five-week dietary menu and knows what will be served at each meal before the staff do.) His tastes in food have broadened and he will now eat some disliked foods or even agree to leave certain foods uneaten on his plate rather than becoming upset.

Programming

IJ can care for his basic needs but is in programs to refine his shaving, toothbrushing, and bathing skills. He enjoys arts and crafts, spends much of his time listening to records, and has been in a program to learn to operate a record and cassette player. He met a sociability goal to attend twenty cottage activities per month and is now in a program to play table games with his peers.

He was placed in the facility prevocational program last year and greatly enjoys his sessions. His motor skills are adequate for the tasks but his present behavior does not permit placement at a work site. His prevocational skills trainer has been able to achieve good control over his behavior and he has recently shown some generalization to another trainer. IJ receives stars on his shirt when he works

appropriately and is very proud of them. The problem of him taking training supplies back to the cottage has been addressed by letting him borrow one or two objects each day and return them the next.

Summary

IJ has made excellent progress in programming, behavioral, and social areas. His tantrums remain somewhat unpredictable although staff are now more aware of his antecedent behaviors and are able to establish control much sooner than previously. The frequency of tantrums has decreased but not enough to refer him to a sheltered work shop site or to reinstate home visits. Any intervention must be strictly behavioral due to his intolerance for psychotropic medication. His impulse control has shown improvement and IJ enjoys being around people more than previously.

IJ's Social Age showed a decrease from 1976 to 1977 (see Figure 5) but has increased steadily ever since. He has lived in two ICF/MR facilities at Sunland and his scores have reflected the same progress in both placements.

IJ's present ICF/MR setting is felt to be the best placement for him at present and it is hoped that he will eventually be able to move to a community ICF/MR which will be located near his family and which can provide the structure necessary to maintain his appropriate behavior.

CASE STUDY #6

Demographics

KL is a thirty-three year old moderately retarded white male who has no physical handicaps except epilepsy, which is controlled by anticonvulsants. He is verbal but difficult to understand. KL has lived at Sunland since he was eleven and in his present ICF/MR cottage since the age of thirty.

Behavior

KL is physically very strong and can become extremely destructive and violent with both peers and staff. In past years his verbal statements were often inappropriate no matter what his mood. Typical responses to someone merely saying "hello" included cursing, statements of "you don't like me," and threats to kill himself. (The latter have been attention-seeking threats only as he has never engaged in any self-abusive or suicidal behaviors.)

Behavioral control has been achieved primarily through consistent extinction of KL's inappropriate verbalizations. Facility staff who know him have been successful in ignoring his behavior but people who don't know him well find it difficult to tolerate his insults and noncompliance. KL's behavior escalates quickly and he will aggress

if staff become angry or try to order him around. It has therefore been necessary to withdraw him from some training programs and provide the services through his own unit.

The joint efforts of cottage and training staff have helped KL to achieve some control over his outbursts. His skills and attitude have shown such improvement that staff are now able to address his noncompliance and inappropriate verbalizations. A nursing program for KL to take his daily medications without cursing at the nurse has been successful. Altercations with peers continue but staff are often able to prevent them by separating the antagonists at the first sign of trouble. His dosage of 200 milligrams of Mellaril daily was successfully lowered to 100 milligrams in 1983. It is hoped that the dosage can be further lowered and eventually discontinued as his behavior continues to show improvement.

Programming

KL's progress in his training programs has been dependent on his moods and behavior. Most social interactions and training demands in past years were met with verbal aggression, but KL now appears happy much of the time and seems to be proud of his training progress.

KL met the program goal to take medications and is now learning to care for first aid needs. He is in a sign language interaction program which, it is hoped, will teach appropriate group interaction and improve his rocky relationship with a deaf cottage mate. He is receiving speech therapy for articulation and intelligibility. Efforts

to teach him to lace and tie his shoes failed dismally (hello, Velcro!) but mending skills appear hopeful. He performs various janitorial duties in prevocational training with the emphasis on compliance and appropriate verbal behavior.

KL has all the skills necessary for a paid position in the vocational training department but his behavior remains a hindrance. His progress has been significant but is not yet to the point where he is expected to be able to maintain control in an environment other than his own unit.

Summary

Figure 6 illustrates the pattern of KL's Social Age scores during his time at Sunland. The strong initial downward trend evident since 1978 was reversed after his first year in ICF/MR and continues to show strong improvement although it has not yet returned to the 1976 level. The decrease in Social Age from 1978 to 1981 did not reflect any deterioration of actual ability but rather the effects of KL's problematic behavior.

KL's present cottage and training programs are able to provide relative consistency and he has responded very well. Outbursts occur once or twice per month and he is becoming more mature in his interactions with others. While the actual frequency of inappropriate behavior is down only slightly from the 1982 average of three episodes per month, the intensity of such outbursts has greatly decreased.

KL continues to benefit from the structure provided through his Sunland ICF/MR placement. His adaptive skills are adequate for

placement elsewhere but he lacks the necessary behavioral control. It is anticipated that a community placement will be appropriate for him in three to five years. Such a placement must provide structure and consistency, and staff will require enough behavioral expertise to be able to ignore insults and still reinforce KL's appropriate behaviors. Given such support, KL will probably do well outside of the institution. If appropriate structure is not provided, however, he will most likely have serious outbursts and be returned to Sunland since his behavior is so dependent on its consequences.

CASE STUDY #7

Demographics

MN is a twenty-six year old black male who has resided at Sunland since the age of sixteen and in his present ICF/MR cottage since the age of twenty-two. The cause of his retardation is unknown; he scores in the moderate range intellectually and the mild range adaptively. He is well developed physically, has no known handicaps, and has excellent language skills.

Behavior

MN's behavior is usually appropriate. He is sociable and very much enjoys the company of staff persons, but tends to avoid his peers. He initiates conversations with others but rarely discusses topics relevant to the time or the situation, perseverating instead about unrelated topics such as "green apples" and "getting out of here." He also frequently uses a high, female voice patterned after a character on a favorite television show or a low, deep voice when he is very upset and almost out of control. It is not known whether his voices result from a delusional process, his reinforcement history, or a combination of the two.

MN will usually speak in an appropriate pitch if ignored or told to use his "real" voice. Staff who do not know him or who think the

high voice is cute give him attention for using it. He becomes angry and aggressive if teased about being a girl and so his vocational training job site has been carefully selected to bring him into contact with staff who respond appropriately to his voices.

MN's daily dose of 100 milligrams of Mellaril was discontinued in 1982 due to behavioral improvement. The medication was soon reinstated after he became less sociable, more agitated, used his low voice frequently, and stopped responding to requests to use his normal voice. His response to the discontinuation of antipsychotic medication suggests that the voices are psychotic in nature; his response to extinction and social disapproval supports a behavioral etiology. The voices are probably due to a combination of the two factors and require both psychotropic medication and behavioral consequences.

MN is generally responsive to staff intervention but when extremely angry becomes dangerous. Aggressive outbursts occur on the average of once each year and usually result in injury to the person being attacked. Formal behavioral programming has not been implemented because of the low frequency of his outbursts. Both staff and peers are aware of the explosive nature of MN's outbursts and are careful to defuse situations before he loses control. He is nonetheless treated firmly and consistently and outbursts do not go unsequated.

Programming

MN functions at a high level and his progress reflects his abilities. Basic skills are adequate and so programming focuses on skills such as cleaning and cooking, basic reading and math, and

self-administration of medication under supervision. He has met goals to buff the floor, sew on buttons, iron clothes, and use the washer and dryer. He attends school and works at the wood shop making surveyor stakes. Goals to complete crafts projects and to play cards with peers address his social skills.

Summary

MN's progress (see Figure 7) since admittance to ICF/MR has been strong. The drop in his Social Age in 1984 is not felt to reflect a decrease in his functioning but rather corrects the elevated score of 1983 which was given by a temporary and inexperienced tester. MN continues to profit from a training atmosphere but it is felt that his skills are adequate for community placement. He will require a group living home that sets firm limits and provides good structure, as well as psychiatric follow-up to monitor the effects of his medication. MN talks about "getting out of here" (Sunland) and moving to a group living home and is expected to enjoy the change when it occurs.

CASE STUDY #8

Demographics

KF is a twenty-five year old white female who is profoundly retarded due to Down's Syndrome. She has been a resident at Sunland since the age of five and has lived in the same ICF/MR cottage since 1980. Her hearing and vision are normal, she is nonverbal, and has no physical handicaps. Surgery in 1974 for congenital heart disease was successful and there are no restrictions on her level of activity.

Behavior

KF exhibits mild self-stimulatory behaviors of twirling objects and of pulling the skin around her eye. She will take food from others at meals if not watched but not to the extent of this being a problem.

In 1981 KF began to spit into the air conditioning units and onto the floor. In 1982 she stopped spitting but began to vomit, apparently on demand. Medical tests were negative, and doses of Maalox, Tagumet, and a bland diet were equally ineffective in controlling the vomiting. The frequency of incidents increased from 3-6 times per week to 15-20 incidents per week and KF's weight dropped. Incidents decreased when she began prevocational training classes and then increased again when sessions were temporarily suspended for several weeks. Once classes

started up again vomiting only occurred in the waiting room and stopped when she was given a magazine to occupy her time.

It appears that the vomiting was of behavioral origins and a response to boredom. KF has had several changes of schedule since the vomiting stabilized and appears to have accepted them well. There have been no reoccurrences.

Programming

In addition to self-care and academic skills, KF's programs have addressed her attention span and social skills. She is presently able to stay on task 13 minutes as opposed to the 30-60 seconds reported in 1981, and has met goals to trace a line and interact in a group.

Summary

KF's adaptive growth pattern has been variable (see Figure 8) but an overall upward trend is evident. She has begun to "blossom" and is an outgoing and happy person compared to the shy and withdrawn individual of a few years ago. Progress in formal program goals has been slow but, socially and emotionally, KF has "come alive." She is now displaying more behaviors of all types, and her training must shape the desirable ones and extinguish any inappropriate behaviors. KF's vomiting is an example of such behavior and fortunately has been replaced with more positive ways of influencing her environment.

CASE STUDY #9

Demographics

CJ is a sixteen year old severely retarded black female. The cause of her retardation is unknown and she has no physical handicaps. There is some question of possible temporal lobe (psychomotor) seizures but electroencephalogram (EEG) results have been inconclusive. She has lived in foster homes and attended public school but the severity of her behavior problems necessitated placement at Sunland. She was institutionalized in 1981 and moved from a non-ICF/MR cottage to her present one that same year.

Behavior

CD is very aggressive and destructive. The sudden and unpredictable nature of her outbursts suggests possible psychomotor seizure activity but anticonvulsant therapy has been ineffective in controlling her behavior. She presently receives Thorazine, Lithium, and Tegretol. Numerous medications and behavioral approaches have been attempted, all unsuccessful. The other residents in the cottage are often bitten by her for no apparent reason and with no warning. Additionally, she damages property on hers and surrounding cottages, has injured staff, and requires five staff to restrain her despite her fairly small size.

CJ is responsive to staff attention at times but usually seems to be in a "daze" which is punctuated by sudden incidents of aggression. These incidents often occur during social events when she appears to be enjoying herself and, without any warning whatsoever, will bite any peers who have the misfortune to be sitting near her.

Reinforcers have remained effective with CJ for only very short periods of time, usually two to three days. She has rejected regularly scheduled staff attention, torn up the radio purchased for her, and refused to go on the walks she enjoyed at other times. An attempt to maintain her interest by allowing her to choose from a variety of reinforcers failed miserably when she fixated on the chocolate cake being offered and tantrumed until 3 A.M.

Staff who worked with CJ prior to her Sunland placement report that her behavior has always been unpredictable and inappropriate. She frequently runs away from the cottage in search of bugs and frogs and, at a previous placement, was reportedly found in a swamp area playing with a rattlesnake. Most animals do not survive her attentions and so are not suitable reinforcers for appropriate behavior.

Programming

CJ's response to programming has been poor. She often refuses to attend on-cottage training sessions and runs away from the off-cottage school on many of the days she does choose to attend. Her strength and resistance to consequences make ensuring compliance difficult.

Comments

The interdisciplinary team feels that CJ is inappropriate placed at Sunland and in the ICF/MR program. Notwithstanding the increase in her social age scores since ICF/MR placement (see Figure 9), she is deriving minimal benefit from the program and poses a substantial danger to her peers. It is not possible to say whether the increase in Social Age has been a result of ICF/MR placement or of institutionalization since she was at Sunland only 7 1/2 months before being moved to ICF/MR.

Efforts are underway to move CJ to a non-ICF/MR cottage where the residents will defend themselves against her attacks. The move is expected to be effective since she attacks mainly clients who will not fight back. The Team agrees, however, that CJ would be more appropriately placed in a psychiatric setting equipped to deal with her unpredictable and bizarre behaviors. Such placement is extremely unlikely since no suitable treatment facility exists for dually diagnosed clients at present.

CASE STUDY #10

Demographics

RW is a twenty-five year old black male who has no apparent physical handicaps and is severely retarded as a result of mild microcephaly (a condition of abnormal smallness of the head, usually associated with mental defects). His speech is intelligible but usually echolalic (repeats what has just been said to him) or perseverative (talks about the same topic repeatedly and out of context). He has lived at Sunland since the age of sixteen and in ICF/MR since he was twenty-three. Although RW enjoys social activities he generally keeps to himself.

Behavior

RW has a history of inappropriate behaviors such as taking others' belongings, hoarding and burying objects and paper, and taking food from the refrigerator. More seriously, he has started fires in paper or wastebaskets. He has also exhibited sexually aggressive behavior toward female staff and male clients, and worn female underwear. His psychological report of 1981 states that "RW may eventually improve through strict monitoring and return of pilfered items, and appropriate handling of possessions of his own. However, the prognosis is poor for effectively changing these problematic behaviors."

There has been improvement since the move to his present cottage but RW must still be closely monitored. Matches were found on him once in 1982 and one wastebasket fire was reported. He continues to search the garbage and eat food scraps but opportunities to do so have been restricted. No sexual behaviors have been reported at his present cottage but he did develop the behavior of tearing his clothes in hopes of getting new ones. Shopping is a positive event for the clients and attractive, stylish clothing is purchased. RW had new clothing but apparently wanted to go shopping again. New clothes were not purchased after tearing incidents and the behavior extinguished.

In 1983 RW began to experience possible "flashbacks." He would talk about a previous placement, verbally reprimand himself for being a "bad boy" and cringe as though avoiding a blow. Inquiries at the previous placement gave no clues and it was not known why such behavior occurred two years after the transfer to his present cottage. RW also became very unresponsive and made threatening gestures to some previously liked staff when approached. He would put his hands over his ears and walk away, as though trying to block out sounds. He showed spontaneous improvement after several months and has remained stable since that time.

Even when apparently happy, RW appears to maintain minimal contact with reality. A low dose of Haldol was prescribed in 1984 in an attempt to improve this condition but was discontinued when he showed no apparent response.

Programming

RW has well-developed self-care skills and is receiving training in kitchen and cleaning tasks. Academic performance has been minimal and has not progressed past basic color and object identification. A goal to play table games with peers was somewhat successful in encouraging social contact, and RW is doing well in the vocational training ceramics program.

Summary

RW receives a fairly wide range of on- and off-cottage programming. While his progress in actual tasks has been minimal he does appear to have benefitted from the attending, on-task and socialization aspects of his training. His Social Age scores (see Figure 10) show a steady upward trend but also a great deal of variability. A small downward trend began in 1980 but his score fell sharply immediately after his move to ICF/MR in 1982. The lower score was due primarily to RW's fire setting tendencies and the resultant need to escort him to all destinations. Improvement in his behavior is reflected in his high social age in 1983, and the slight variability continues in 1984. Small differences in score are expected due to the VSMS's interview format and are not considered important.

The interdisciplinary team agrees that RW's skills are now adequate for placement in an ICF/MR facility located in the community and that he may be able to live in a group living home some day. Staff who work

with RW must have some behavioral expertise and provide close supervision to prevent any recurrences of previous inappropriate behaviors.

CASE STUDY #11

Demographics

JF is a thirty-two year old white female who is profoundly retarded due to unknown causes. She was institutionalized at the age of six and has lived in ICF/MR for the past four years. She has no sensory deficits but her physical appearance is deformed. Her jaw structure is off-balance and she holds her mouth open, which results in frequent drooling. Her balance is functionally adequate but she often stands bent over, twirls and stumbles, and hides her face in her hands.

Behavior

JF has a history of severe aggression and self-abuse which necessitated continual physical restraints in earlier years. At present she bangs her head on the wall about once per month and no longer causes tissue damage. Aggression is also infrequent and usually occurs in retaliation to attacks against her. She grinds her teeth (bruxes) very loudly. This behavior is of concern because of potential dental problems, not to mention its unpleasantness for the people around her (like fingernails on a chalk board!). A DRO program to decrease bruxing by praising her when she was quiet was discontinued when the intervention resulted in an increase in frequency. The behavior has begun

to show some improvement since then through regular social disapproval consequences.

As stated earlier, JF's balance is functional but she frequently stumbles and falls, apparently an attention-seeking device. She receives occupational therapy to improve her balance and, additionally, staff ignore inappropriate stumbles.

JF's moods are extreme and involve loud screaming when she is upset or wild laughter when happy. She resists changes in her established routine and does not like to be away from the cottage for extended periods of time. Staff must unfortunately avoid becoming JF's "favorite" since she will become overly attached and behave inappropriately. She becomes very upset on their days off or if their schedule is changed and has been known to try to block a favored person's car when they try to leave work.

JF received Mellaril in the past to help control her behavior. A dosage taper began in 1980 and reductions continued until all medication was successfully discontinued in 1982.

Programming

JF possesses basic self-care skills and is refining them through training. She also attends the off-cottage facility school and prevocational training programs. Her overall training focus at present is directed toward developing and improving her attending skills and participation in off-cottage activities.

Speech therapy in the past has addressed speech, gestures, and signs as modes of communication for JF. Present therapy is directed

toward improving her verbal intelligibility and progress has been steady, including some generalization to the cottage. JF is speaking more and is easier to understand although she is still far from having adequate communication skills. Since she becomes upset when staff cannot understand her any speech progress positively affects her overall behavior and development as well.

Occupational therapy has addressed her drooling problem and she progressed to the point of being able to control her saliva for an entire thirty-minute session. Some drooling continues but at a reduced rate, and OT is now working on improving her balance.

OT has enrolled JF in the horsemanship program at Sunland. This nationally developed program teaches handicapped persons to care for and ride extremely gentle and well-trained horses. Goals include improved balance and motor skills as well as improved self-esteem for individuals who may have control over their movements for the first time in their lives. JF is presently grooming the horse and refuses to mount, but it is anticipated that the muscles involved in staying on a horse will further enhance her balance once she gets over her fear. Additionally, she must behave appropriately around the horse and not scream, stumble, or twirl.

Summary

As shown by her Social Age scores (see Figure 11) JF made steady progress for two years after ICF/MR admittance and then stabilized after a slight regression. She continues to benefit from ICF/MR but in areas that are either not reflected in her Social Age score or have

not improved enough to be credited. Development continues to be seen in her improved social skills, communication and balance, and decreased bruxism.

The interdisciplinary team has recommended community ICF/MR placement in three to five years but feels that JF will require Sunland ICF/MR until then, especially in light of her present inability to accept change or be away from the cottage for extended periods of time.

CASE STUDY #12

Demographics

DF is a twenty year old profoundly retarded black female who has no physical disabilities and who is extremely powerful despite her low activity level. She is probably actually functioning in the severe range of mental retardation but scores lower due to her lack of cooperation during testing. She has lived at Sunland since the age of twelve and in ICF/MR since the age of seventeen.

Behavior

DF is moody and her behavior reflects her mood. At present she is uncooperative and has become aggressive toward staff. The aggression usually occurs without any warning or apparent reason and is a matter of concern because of her strength. Other problematic behaviors are destruction and walking off from the cottage in search of sexual partners. The approved ACT (Aggression Control Techniques) procedures are not used to help control DF since any attempt to do so would probably result in serious injury to staff. She is controlled as well as possible through verbal intervention and has recently begun to receive a small dose of Librium in an attempt to reduce her aggression. Attempts at formal behavioral intervention have been unsuccessful since no effective reinforcers or consequences have been found.

Programming

Program benefits have been questionable for DF. She is doing well refining her existing self-care skills but shows a great deal of resistiveness in other training areas, refusing almost half of her sessions at times. Changes in task, trainer, session times, and reinforcers have been ineffective. DF began receiving occupational therapy earlier this year in order to improve her perceptual skills but was dropped from the program due to a lack of progress and cooperation. She has progressed fairly well in prevocational janitorial skills training, but her moods affect her performance there as well. Her skills are adequate for a paying job in the vocational training department but DF has refused all attempts to take her to job sites for assessment.

Comments

Last year the interdisciplinary team recommended a Sunland non-ICF/MR placement for DF due to her apparent lack of benefit from the ICF/MR program. A review of her training history over the past four years suggests that she is most likely to show an interest in the areas of self-care and daily living skills and least likely to participate in academic-type programs. She enjoys some leisure time activities but only selectively and generally keeps to herself.

A non-ICF/MR cottage would provide training and activities but less structure than ICF/MR. DF's Social Age scores since her placement at Sunland (see Figure 12) show a strong upward trend for the period

1977-1980 when she lived in a non-ICF/MR cottage but a dramatic reversal after her placement in ICF/MR (second 1980 score), which strongly suggests that she may respond better to a more unstructured environment.

DF did make some progress during the past year and ICF/MR placement was once again recommended at her 1984 hab plan. Her Social Age is close to its 1980 level (first 1980 score) but it is impossible to project her performance during the coming year because of her moodiness and behavior.

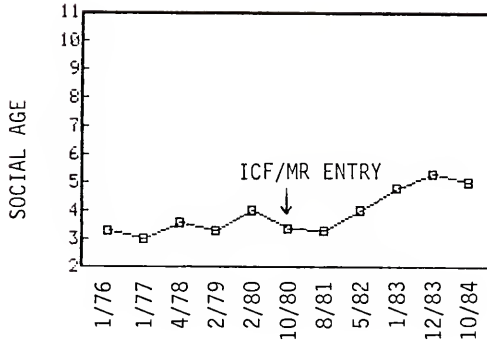


Figure 1. VSMS scores for subject AB (Case Study 1).

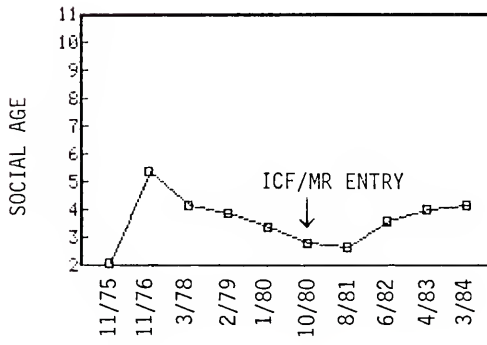


Figure 2. VSMS scores for subject CD (Case Study 2).

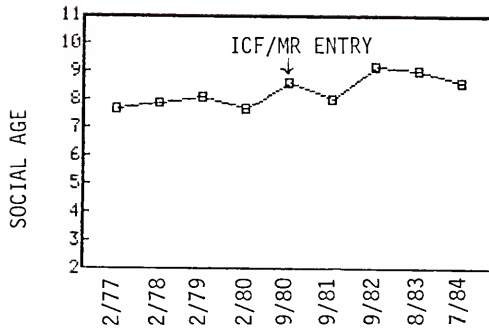


Figure 3. VSMS scores for subject EF (Case Study 3).

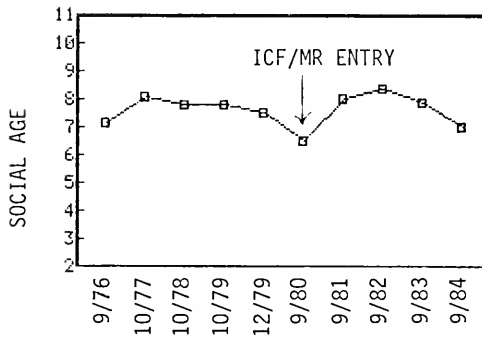


Figure 4. VSMS scores for subject GH (Case Study 4).

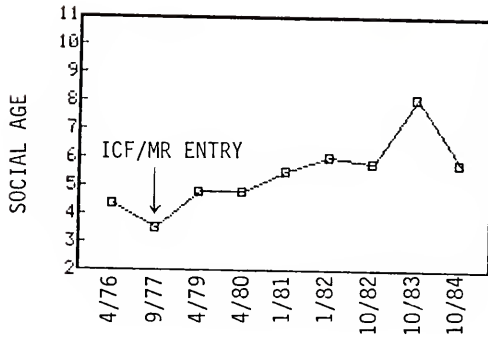


Figure 5. VSMS scores for subject IJ (Case Study 5).

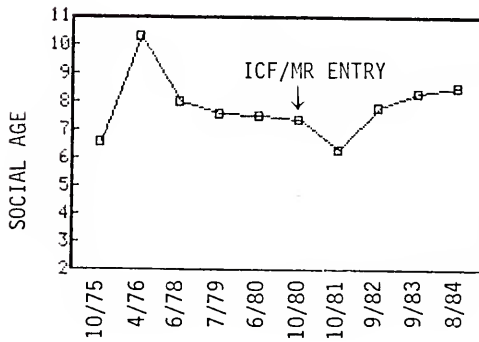


Figure 6. VSMS scores for subject KL (Case Study 6).

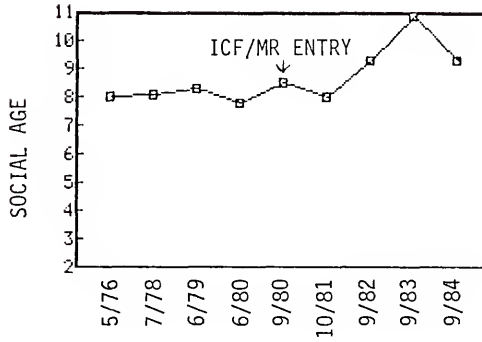


Figure 7. VSMS scores for subject MN (Case Study 7).

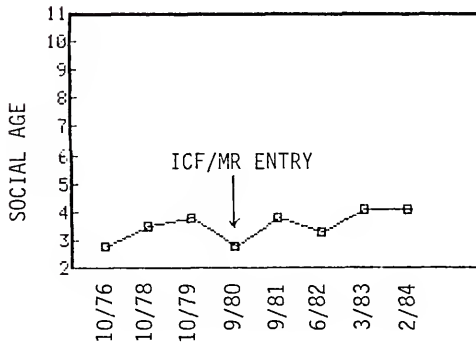


Figure 8. VSMS scores for subject KF (Case Study 8).

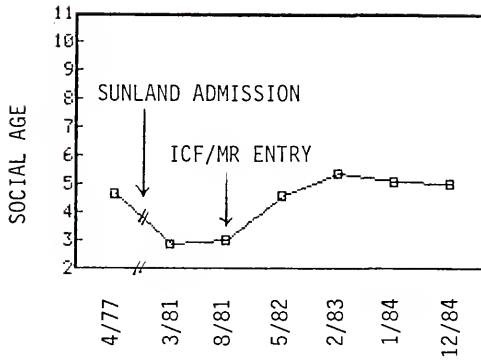


Figure 9. VSMS scores for subject CJ (Case Study 9).

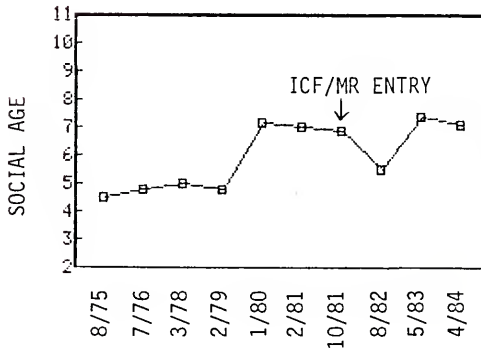


Figure 10. VSMS scores for subject RW (Case Study 10).

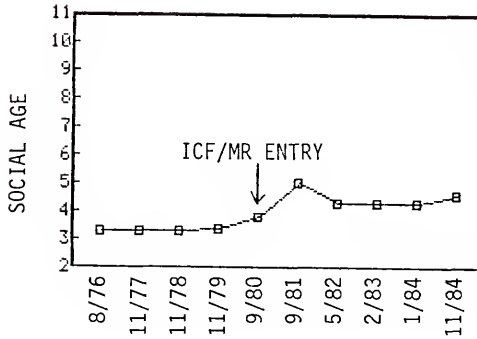


Figure 11. VSMS scores for subject JF (Case Study 11).

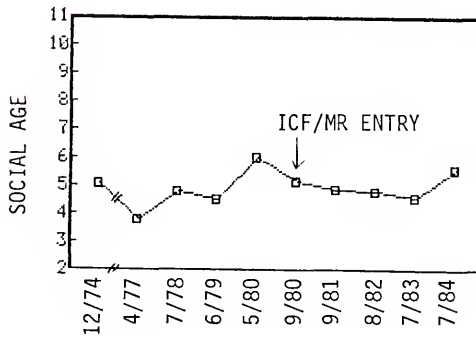


Figure 12. VSMS scores for subject DF (Case Study 12).

APPENDIX C
CASE STUDY CONSENT FORM

STATEMENT OF CONSENT

A study is being conducted to examine the effects of ICF/MR placement and training on clients at Sunland Center Gainesville. In order to examine some of the factors involved in client growth, individual case studies will be conducted. Client identities will be kept completely confidential. Information for each study will be obtained from the client's annual habilitation plan, monthly progress notes, and observations made by the investigator.

Training progress and any factors that may have influenced this progress will be discussed.

This study has been approved by the Sunland Research Committee and by Mr. Max Jackson, Superintendent, Sunland Center Gainesville.

I agree that the above case study may be written about my son/daughter/guardee. I understand that identities will be kept confidential and that the study will in no way intrude on client rights or privacy.

Subject

Parent/Guardian

Susan Bedinger, Residential Services Supervisor
Facility III, Sunland Center Gainesville
Phone: (904) 395-1592.

Investigator's name and address

APPENDIX D
SUMMARY OF ANALYSIS OF VARIANCE FOR MODERATELY RETARDED
SUBJECTS AFTER THREE YEARS IN ICF/MR

Source	Degrees of Freedom	Mean Square	F	Probability
Between Subjects				
Treatment	1	24.73	2.13	0.14
Error	63	11.63		
Within Subjects				
VSMS	4	5.37	7.19	0.00
Treatment x VSMS	4	3.90	5.23	0.00
Error	252	0.74		
VSMS Means	ICF/MR	SD	Non-ICF/MR	SD
Sunland entry	7.10	1.05	6.80	2.37
ICF/MR entry	7.30	1.55	6.97	1.56
One year	7.22	1.52	6.83	1.50
Two years	8.37	1.54	6.97	1.52
Three years	9.04	2.16	7.00	1.44

APPENDIX E
SUMMARY OF ANALYSIS OF VARIANCE FOR SEVERELY RETARDED
SUBJECTS AFTER FOUR YEARS IN ICF/MR

Source	Degrees of Freedom	Mean Square	F	Probability
Between Subjects				
Treatment	1	32.83	3.45	0.06
Error	50	9.52		
Within Subjects				
VSMS	5	4.47	7.62	0.00
Treatment x VSMS	5	2.10	3.58	0.00
Error	250	0.58		
VSMS Means	ICF/MR	SD	Non-ICF/MF	SD
Sunland entry	3.55	1.06	4.97	1.76
ICF/MR entry	3.90	1.18	5.41	1.38
One year	4.57	1.19	5.23	1.50
Two years	4.84	0.94	5.34	1.42
Three years	4.89	0.97	5.33	1.51
Four years	5.09	1.18	5.47	1.40

APPENDIX F
SUMMARY OF ANALYSIS OF VARIANCE FOR PROFOUNDLY RETARDED
SUBJECTS AFTER FOUR YEARS IN ICF/MR

Source	Degrees of Freedom	Mean Square	F	Probability
Between Subjects				
Treatment	1	104.58	19.10	0.0
Error	318	5.47		
Within Subjects				
VSMS	5	9.52	45.31	0.0
Treatment x VSMS	5	3.39	16.14	0.0
Error	1590	0.21		
VSMS Means	ICF/MR	SD	Non-ICF/MR	SD
Sunland entry	1.76	0.76	2.42	1.33
ICF/MR entry	1.96	0.78	2.73	1.12
One year	2.21	0.83	2.71	1.10
Two years	2.29	0.90	2.64	1.05
Three years	2.34	0.97	2.59	1.04
Four years	2.45	1.04	2.74	1.19

APPENDIX G
SUMMARY OF ANALYSIS OF VARIANCE FOR PROFOUNDLY RETARDED
HANDICAPPED ICF/MR SUBJECTS AFTER FOUR YEARS IN ICF/MR

Source	Degrees of Freedom		Mean Square	F	Probability	
Between Subjects						
Group	2		42.45	11.94	0.00	
Error	135		3.55			
Within Subjects						
VSMS	5		2.87	22.02	0.0	
Group x VSMS	10		0.16	1.23	0.26	
Error	675		0.13			

VSMS Means	No Handicap	SD	One Handicap	SD	Two or More Handicaps	SD
Sunland entry	1.87	0.79	1.74	0.58	0.83	0.32
ICF/MR entry	2.14	0.73	1.77	0.73	0.97	0.46
One year	2.39	0.81	2.08	0.68	1.08	0.44
Two years	2.48	0.86	2.17	0.86	1.13	0.43
Three years	2.52	0.96	2.22	0.91	1.17	0.35
Four years	2.64	1.01	2.32	1.04	1.21	0.39

APPENDIX H
ADAPTIVE LEVEL AND ITS RELATIONSHIP TO CHRONOLOGICAL AGE
AND LEVEL OF RETARDATION (IQ) FOR ALL CONTROL SUBJECTS
AND FOR SUBJECTS WHO LIVED IN
ICF/MR AT LEAST ONE YEAR

	Social Age
	N = 551
Chronological age	0.13
IQ	-0.62*

APPENDIX I
ADAPTIVE LEVEL AND ITS RELATIONSHIP TO AGE AT INSTITUTIONALIZATION,
YEARS LIVED IN NON-ICF/MR, AND AGE AT ENTRY TO
ICF/MR FOR ALL ICF/MR SUBJECTS

	Social Age
	N = 330
Age at institutionalization	0.10
Years lived in Sunland non-ICF/MR	-0.23
Age at entry to ICF/MR	-0.13

REFERENCES

- Administration argues to cut rights of regarded. (1984, April 26). Gainesville Sun, p. 5-A.
- AFSCME. (1984). Patients for sale: The plight of Florida's mentally ill and retarded. Washington, D.C.: AFSCME.
- Anderson, R.L. (1981). Mental retardation. In Woody, R.H. (Ed.), Encyclopedia of clinical assessment, Volume II (pp. 714-728). San Francisco: Jossey-Bass Publishers.
- Balla, D. (1976). Relationship of institution size to quality of care: A review of the literature. American Journal of Mental Deficiency, 81, 117-124.
- Balla, D., Butterfield, E., & Zigler, E. (1974). Effects of institutionalization on retarded children: A longitudinal cross-institutional investigation. American Journal of Mental Deficiency, 78, 530-549.
- Bailey, J. (1981). Wanted: A rational search for the limiting conditions of habilitation in the retarded. Analysis and Intervention in Developmental Disabilities, 1, 45-52.
- Baroff, G.S. (1980). On size and the quality of residential care: A second look. Mental Retardation, 18, 113-117.
- Bates, C. (1984). Initial data for compliance with HRSR 95-3. Unpublished paper, Sunland Center, Gainesville, Florida.
- Bates, C. (1985). Annual psychotropic review. Unpublished report, Sunland Center, Gainesville, Florida.
- Bedinger, S., & Miles, V. (1982). Effects of ICF/MR placement on Vineland Adaptive Level Scores. Poster sessions presented at FABA conference, Orlando, Florida, and at AAMD conference, Sarasota, Florida.
- Bedner, M.J. (1974). Architecture for the handicapped in Denmark, Sweden, and Holland: A guidebook to normalization. Ann Arbor: University of Michigan.

- Bell, C.W. (1974). A resource guide for group homes for the developmentally disabled in the State of Washington. Olympia, Washington: Office of Developmental Disabilities, Department of Social and Health Services.
- Bible, G.H., & Sneed, T.J. (1976). Some effects of an accreditation survey on program completion at a state institution. Mental Retardation, 14(5), 14-15.
- Bjaanes, A., & Butler, E.W. (1974). Environmental variation in community care facilities for mentally retarded persons. American Journal of Mental Deficiency, 78, 429-439.
- Blatt, B. (1981). In and out of mental retardation: Essays on educability, disability and human policy. Baltimore: University Park Press.
- Blindert, H.D. (1975). Interactions between residents and staff. Mental Retardation, 13(4), 38-40.
- Braginsky, D.D., & Braginsky, B.M. (1971). Hansels and Gretels: Studies of children in institutions for the mentally retarded. New York: Holt, Rinehart, & Winston.
- Campbell, A.C. (1971). Aspects of personal independence of mentally subnormal and severely subnormal adults in hospital and in local authority hostels. International Journal of Social Psychiatry, 17, 305-310.
- Close, D.W. (1977). Community living for severely and profoundly retarded adults: A group home study. Education and Training of the Mentally Retarded, 12, 256-262.
- Cochran, W.E., Sran, P.K., & Varano, G.A. (1977). The relocation syndrome in mentally retarded individuals. Mental Retardation, 15(2), 10-12.
- Coffman, T.L., & Harris, M.C. (1980). Transition shock and adjustments of mentally retarded persons. Mental Retardation, 18(1), 3-7.
- Cohen, H., Conroy, J.Q., Frasier, D.W., Snelbecker, G.E., & Spreat, S. (1977). Behavioral effects of interinstitutional relocation of mentally retarded residents. American Journal of Mental Deficiency, 82, 12-18.
- Conroy, J.W. (1979, October). Report on assessment of institutional environments. Philadelphia, Pennsylvania: Developmental Disabilities Center.

- Conroy, J.W., & Bradley, V.J. (1981, October). The Pennhurst Longitudinal Study: What has been learned to date? A report prepared under contracts with the U.S. Department of Health and Human Services, Office of Human Development Services, Region III; John McCann, Project Officer, Philadelphia.
- Conroy, J.W., Efthimiou, J., & Lemanowicz, J.A. (1980, November). Matched comparison study of adaptive behavior growth among deinstitutionalized clients. Philadelphia, Pennsylvania: Developmental Disabilities Center.
- Conroy, J.W., & Lemanowicz, J.A. (1981, March). Developmental growth among the residents of Pennhurst: What factors are related to growth? Philadelphia, Pennsylvania: Developmental Disabilities Center.
- Cruickshank, W.M. (1970). Review. In Buros, O.K. (Ed.), Personality tests and reviews (pp. 574-575). Highland Park, New Jersey: The Gryphon Press.
- Crunk, W.A.(1982, Feb.) Letter to colleague. (Available from W.A. Crunk, Regional Administrator, Office of Human Development Services, 3535 Market Street, Philadelphia, Pennsylvania.)
- Dailey, W., Allen, G., Chinsky, J., & Veit, S. (1974). Attendant behavior and attitudes toward institutionalized children. American Journal of Mental Deficiency, 78, 586-591.
- DeGennaro, M., Hymen, R., Crannell, A.M., & Mansky, P. (1981, July). Antidepressant drug therapy. American Journal of Nursing, 1304-1309.
- Dentler, R.A., & Mackler, B. (1961). The socialization of retarded children in an institution. Journal of Health and Human Behavior, 2, 243-252.
- DeVellis, R.F. (1977). Learned helplessness in institutions. Mental Retardation, 15(5), 10-13.
- Doll, E.A. (1964). Vineland Scale of social maturity. Minneapolis: American Guidance Service.
- Dondey, M. (1982, May). A model program for the transition state of deinstitutionalization. Annual Conference of the American Association on Mental Deficiency, Boston.
- Edgerton, R.B. (1975). Issues relating to the quality of life among mentally retarded persons. In Begab, M.J., & Richardson, S.A. (Eds.), The mentally retarded and society: A social science perspective. Baltimore: University Park Press.

- Ellis, N.R., Balla, D., Estes, O., Warren, S.A., Meyers, C.E., Hollis, J., Isaacson, R.L., Palk, B.E., & Siegel, P.S. (1981). Common sense in the habilitation of mentally retarded persons: A reply to Menolascino and McGee. Mental Retardation, 19(5), 221-225.
- Ellison, D. (1983). Adaptive behavior change in institutionalized profoundly retarded women in an ICF/MR cottage. Columbus: Ohio State University.
- Eyman, R.K., & Borthwick, S.A. (1980). Patterns of care for mentally retarded persons. Mental Retardation, 18, 63-66.
- Eyman, R.K., Silverstein, A.B., & McLain, R. (1975). Effects of treatment program on the acquisition of basic skills. American Journal of Mental Deficiency, 79, 573-582.
- Finn, J.D. (1983). Multivariate approaches to the evaluation of programs for mildly mentally retarded persons. American Journal of Mental Deficiency, 88(3), 263-269.
- Fromme, D.K. (1974). On the use of the Vineland Social Maturity Scale as an estimate of intellectual functioning. Journal of Clinical Psychology, 30(1), 67-68.
- Furfey, P.H. (1970). In Buros, O.K. (Ed.), Personality tests and reviews (pp. 257-258). Highland Park, New Jersey: The Gryphon Press.
- Gardner, J.M., & Giampa, F.L. (1971). Utility of three behavioral indices for studying severely and profoundly retarded children. American Journal of Mental Deficiency, 76(3), 352-356.
- Gibson, D., & Fields, D.L. (1983). Fifty years of institutional habilitation outcomes: Inventory and implications. Education and Training of the Mentally Retarded, 18(2), 82-89.
- Grant, G.W.B., & Moores, B. (1977). Resident characteristics and staff behavior in two hospitals for mentally retarded adults. American Journal of Mental Deficiency, 82, 259-265.
- Green, C., & Zigler, E. (1962). Social deprivation and the performance of retarded and normal children on a satiation type task. Child Development, 33, 499-508.
- Grossman, H.J. (Ed.). (1977). Manual on terminology and classification in mental retardation. Baltimore: Garamond/Pridemark Press.
- Halderman v. Pennhurst State School and Hospital et al. 74-1345, March 1978.
- Harris, E. (1981a, July). Antipsychotic medications. American Journal of Nursing, 1316-1323.

- Harris, E. (1981b, July). Extrapramidal side effects. American Journal of Nursing, 1324-1328.
- Harris, E. (1981c, July). Lithium. American Journal of Nursing, 1310-1315.
- Harris, E. (1981d, July). Sedative-hypnotic drugs. American Journal of Nursing, 1329-1334.
- Harris, J., Veit, S., Allen, G., & Chinsky, J. (1974). Aide-resident ratio and ward population density as mediators of social interaction. American Journal of Mental Deficiency, 79, 320-326.
- Harris, M.C., Coffman, T.L., Noble, B., & VanDerTin, J. (1981). The effect of training stress on transition adjustment of mentally retarded persons. Unpublished study.
- Hull, J.T., & Thompson, J.C. (1980). Predicting adaptive functioning of mentally retarded persons in community settings. American Journal of Mental Deficiency, 85, 253-261.
- Jordan, N. (1985, February). Reforming a snake pit. Psychology Today, 70-71.
- Kinder, E.F. (1970). Review. In Buros, O.K. (Ed.), Personality tests and reviews. Highland Park, New Jersey: The Gryphon Press.
- Kirk, R.E. (1968). Experimental design: Procedures for the behavioral sciences. Belmont, California: Brooks/Cole Publishing Company.
- Kleinberg, J., & Galligan, B. (1983). Effects of deinstitutionalization on adaptive behavior of mentally retarded adults. American Journal of Mental Deficiency, 88(1), 21-27.
- Lakin, C.K., Krantz, G.C., Bruininks, R.H., Clumpner, J.L., & Hill, B.K. (1982). One hundred years of data on populations of public residential facilities for mentally retarded people. American Journal of Mental Deficiency, 87, 1-8.
- Landesman-Dwyer, S. (1981). Living in the community. American Journal of Mental Deficiency, 86, 223-234.
- Landesman-Dwyer, S., Sackett, G.P., & Kleinman, J.S. (1980). Relationship of size to resident and staff behavior in small community residences. American Journal of Mental Deficiency, 85, 6-17.
- Lemanowicz, J., Feinstein, C.S., Efthimiou, J., & Conroy, J.W. (1980). Longitudinal study of the court-ordered deinstitutionalization of Pennhurst: A report on client progress at Pennhurst. Philadelphia, Pennsylvania: Developmental Disabilities Program/UAP, Contract #130-79-3.

- MacEachron, A.E. (1983). Institutional reform and adaptive functioning of mentally retarded persons: A field experiment. American Journal of Mental Deficiency, 88(1), 2-12.
- Macy, T.W. (1977). A study of the factors involved in the reintegration of residents from a state institution into a community setting. Columbus: Ohio State University.
- Macy, T.W. (1983). A resource manual on transitional adjustment of mentally retarded persons. Prepared for the National Association of State Mental Retardation Program Directors, Inc., Maineville, Ohio.
- Mayhew, G.L., Enyart, P., & Anderson, J. (1978). Social reinforcement and the naturally occurring social responses of severely and profoundly retarded adolescents. American Journal of Mental Deficiency, 83, 164-170.
- McCormick, M., Balla, D., & Zigler, E. (1975). Resident-care practices in institutions for retarded persons: A cross-institutional, cross-cultural study. American Journal of Mental Deficiency, 80, 1-17.
- Meyen, E.L. (1978). Exceptional children and youth: An introduction. Denver: Love Publishing Company.
- More help needed for the retarded. (1984, December 8). The Tampa Tribune, p. 13-A.
- Murphy, M., & Zahm, D. (1978). Effect of improved physical and social environment on self-help and problem behaviors of institutionalized retarded males. Behavior Modification, 2, 193-210.
- O'Connor, G. (1976). Home is a good place: A national perspective of community residential facilities for developmentally disabled persons. Washington, D.C.: American Association on Mental Deficiency.
- Repp, A.C., & Barton, L.E. (1980). Naturalistic observations of institutionalized retarded persons: A comparison of licensure decisions and behavioral observations. Journal of Applied Behavior Analysis, 13, 333-341.
- Risley, T. (1982). Address presented at Florida Association of Behavior Analysis Conference, Tampa. FABA Quarterly, 3, 3.
- Rotegard, L.L., Hill, B.K., & Bruininks, R.H. (1983). Environmental characteristics of residential facilities for mentally retarded persons in the United States. American Journal of Mental Deficiency, 88(1), 49-56.

- Rothney, J.W.M. (1970). Review. In Buros, O.K. (Ed.), Personality tests and reviews. Highland Park, New Jersey: The Gryphon Press.
- Sabatino, D.A. (1981). Special education needs. In Woody, R.H. (Ed.), Encyclopedia of clinical assessment, Volume II (pp. 776-789). San Francisco: Jossey-Bass Publishers.
- Sandler, A., & Thurman, S.K. (1981). Status of community placement research: Effects on retarded citizens. Education and Training of the Mentally Retarded, 16(4), 245-251.
- Schroeder, S., & Henes, C. (1978). Assessment of progress of institutionalized and deinstitutionalized retarded adults. Mental Retardation, 16, 147-148.
- Sharp, E.S., & Polson, J.P. (1984, January). Letter to parents, relatives and friends of the retarded. (Available from Mental Retardation Association of Utah, Inc., 211 East 3rd South, Suite 212, Salt Lake City, Utah 84111.)
- Stainback, W., & Stainback, S. (1983). A review of research on the educability of profoundly retarded persons. Education and Training of the Mentally Retarded, 18(2), 90-100.
- Steadham, C. (1983). The impact of ICF/MR on health status of institutionalized developmentally disabled individuals. Paper presented at American Association on Mental Deficiency National Conference, Dallas, Texas.
- Stevenson, H., & Fabel, L. (1961). The effect of social reinforcement on the performance of institutionalized and noninstitutionalized normal and feeble-minded children. Journal of Personality, 29, 136-147.
- Teagarden, F.M. (1970). Review. In Buros, O.K. (Ed.), Personality tests and reviews (pp. 575-576). Highland Park, New Jersey: The Gryphon Press.
- Tizard, J. (1964). Community services for the mentally handicapped. London: Oxford University Press.
- Tjosvold, D., & Tjosvold, M.M. (1983). Social psychological analysis of residences for mentally retarded persons. American Journal of Mental Deficiency, 88(1), 28-40.
- Tognoli, J., Hamad, C., & Carpenter, T. (1978). Staff attitudes toward adult male residents' behavior as a function of two settings in an institution for mentally retarded people. Mental Retardation, 16, 142-146.

- Turnbull, H.R., & Turnbull, A. (1978). Free appropriate public education: Law and implementation. Denver: Love Publishing Company.
- Veit, S.W. (1973). A method for investigating interactions between institutionalized retardates and their attendants. Master's thesis, University of Connecticut.
- Veit, S.W., Allen, G.J., & Chinsky, J.M. (1976). Interpersonal interactions between institutionalized retarded children and their attendants. American Journal of Mental Deficiency, 80, 535-542.
- Warren, S.A., & Mondy, L.W. (1971). To what behaviors do attending adults respond? American Journal of Mental Deficiency, 75, 449-455.
- Williams, R. (1982, May). Preparing the client for transition: What can we do? Annual Conference of the American Association on Mental Deficiency, Boston.
- Witt, S.J. (1981). Increase in adaptive behavior level after residence in an intermediate care facility for mentally retarded persons. Mental Retardation, 19, 75-79.
- Wyatt v. Stickney et al. Civil Action No. 3195-N, Adequate habilitation for the mentally retarded. District Court of the United States for Middle District of Alabama, Northern Division, February 28, 1972.
- Zigler, E. (1961). Social deprivation and rigidity in the performance of feebleminded children. Journal of Abnormal and Social Psychology, 62, 413-421.
- Zigler, E. (1963). Rigidity and social reinforcement effects in the performance of institutionalized and noninstitutionalized normal and retarded children. Journal of Personality, 31, 258-269.
- Zigler, E. (1978). National crisis in mental retardation research. American Journal of Mental Deficiency, 83, 1-8.
- Zigler, E., & Balla, D. (1972). Developmental course of responsiveness to social reinforcement in normal children and institutionalized retarded children. Developmental Psychology, 6, 66-73.
- Zigler, E., Balla, D., & Butterfield, E.C. (1968). A longitudinal investigation of the relationship between preinstitutional social deprivation and social motivation in institutionalized retardates. Journal of Personality and Social Psychology, 10, 437-445.

BIOGRAPHICAL SKETCH

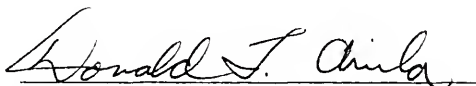
Susan Angenendt Bedinger was born October 14, 1948, in Buffalo, New York. She graduated from Forrest Sherman High School in Naples, Italy, and began college at Stetson University in Deland, Florida, in 1966. She obtained her B.A. in psychology from the University of South Florida in Tampa in 1972 and pursued a supplementary year of study in psychology at the University of Paris, France, in 1974.

After her return to the United States in 1975, Ms. Bedinger worked as a trainer in a grant-funded behavior modification program which demonstrated the ability of profoundly mentally retarded persons to learn academic and self-care skills. Work at Sunland Center was interrupted while Ms. Bedinger completed her M.Ed. and Ph.D. course work at the University of Florida, Gainesville, in educational psychology with minor work in the fields of special education and gerontology. During this time she taught classes in human growth and development and adolescent psychology and also served as coordinator of Project Aid, a program which compliments undergraduate course work with hands-on community experience. She acquired experience in suicide intervention as a telephone counselor at the local crisis center.

Ms. Bedinger returned to Sunland Center after completion of her course work and worked one year as a behavioral specialist, two years as a psychologist, and two years as a unit administrator.

Ms. Bedinger has been employed by the University of Florida since 1979 as an instructor in the Department of Continuing Education where she has helped rewrite and instructs a high school peer counseling course. She is also an ardent flutist and plays in the local community band.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

A handwritten signature in cursive script, reading "Donald L. Avila", written over a horizontal line.

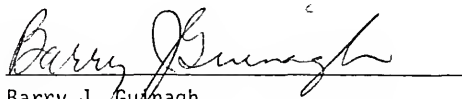
Donald L. Avila, Chairman
Professor of Foundations of
Education

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

A handwritten signature in cursive script, reading "Robert E. Jester", written over a horizontal line.

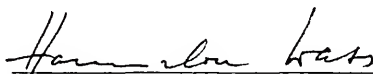
Robert E. Jester
Associate Professor of Foundations
of Education

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

A handwritten signature in cursive script, reading "Barry J. Guynagh", written over a horizontal line.

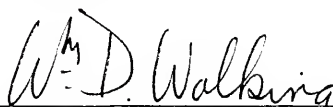
Barry J. Guynagh
Associate Professor of Foundations
of Education

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Hannelore L. Wass
Professor of Foundations of
Education

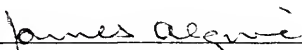
I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



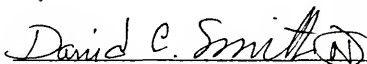
William D. Wolking
Professor of Special Education

This dissertation was submitted to the Graduate Faculty of the College of Education and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

December 1985



Chairman, Foundations of Education



Dean, College of Education

Dean, Graduate School

UNIVERSITY OF FLORIDA



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